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ABSTRACT

This monograph summarizes asthma management conclusions developed by five studies funded under a 5-year federal program titled "Interventions for the Control of Asthma among Black and Hispanic Children." The research goals were to develop model, replicable programs to reduce asthma morbidity; decrease inappropriate use of health care resources; and enhance the quality of life of African American and Hispanic children with asthma. After an introduction, each of the five projects is briefly described. Projects focused on an urban community, a school system, a rural medical care system, a residency training program, and a public health clinic system. Practical insights gained through the projects are organized into three sections: clinical notes, research notes, and public health notes. The section on clinical notes contains insights in two general areas: patient education and management and health professional education. The research notes section, designed for the novice researcher, offers practical tips for all stages of research including pilot studies, patient/participant identification and recruitment, patient/participant retention, staffing, questionnaires and assessment measures, design and assessment of intervention delivery, and data analysis and missing data. The public health notes section covers a variety of issues relevant to the planning and implementation phases of minority asthma interventions. These include educational content and format; modalities of implementation; recruiting, training, and retaining staff and volunteers; and barriers to implementation of intervention. Three appendices list additional minority asthma intervention projects, other resources, and instruments and forms used by the five projects. (Contains approximately 40 references.) (Author/DB)

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Asthma Management in Minority Children:

Practical Insights for Clinicians, Researchers, and Public Health Planners

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National Institutes of Health

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Asthma Managment in Minority Children Working Group Members

Cynthia L. Arfken, Ph.D.
Washington University School of Medicine

David Evans, Ph.D.
Columbia-Presbyterian Medical Center

Edwin B. Fisher, Jr., Ph.D.
Washington University School of Medicine

Humberto A. Hidalgo, M.D.
University of Texas Health Science Center

Jean Hanson, R.N., M.S.N.
University of New Mexico School of Medicine

Floyd Malveaux, M.D., Ph.D.
Howard University College of Medicine

Robert B. Mellins, M.D.
Columbia-Presbyterian Medical Center

Shirley Murphy, M.D.
University of New Mexico School of Medicine

Carmen Ramos, M.D.
New York Bureau of Child Health

Cynthia S. Rand, Ph.D.
The Johns Hopkins Asthma and Allergy Center

Martha Selva, R.N., B.S.N.
University of Texas Health Science Center

Robert C. Strunk, M.D.
Washington University School of Medicine

Linda Sussman, Ph.D.
Washington University School of Medicine

Roslyn Sykes, Ph.D.
Washington University School of Medicine

Lera Thompson, M.S.P.H.
Howard University College of Medicine

Pamela R. Wood, M.D.
University of Texas Health Science Center

National Heart, Lung, and Blood Institute Staff

Ted Buxton, M.P.H.
Special Expert
National Asthma Education and Prevention Program

Leslie Cooper, R.N., M.P.H., Ph.D.
Health Scientist Administrator/Epidemiologist
Division of Lung Diseases

Robinson Fulwood, M.S.P.H.
Coordinator
National Asthma Education and Prevention Program

Suzanne Hurd, Ph.D.
Director
Division of Lung Diseases

James Kiley, Ph.D.
Chief, Airway Biology and Disease Program
Division of Lung Diseases

Ellen Sommer
Public Affairs Specialist
Office of Prevention, Education, and Control

Virginia Silver Taggart, M.P.H.
Health Specialist Administrator
Division of Lung Diseases

R.O.W. Sciences, Inc., Support Staff

Lisa Caira

Maxine Forrest

Special thanks to the following for their input and review of this document:

William C. Bailey, M.D.
University of Alabama at Birmingham

L. Kay Bartholomew, Ed.D., M.P.H.
University of Texas Health Science Center

Robin Bryan
Allergy and Asthma Network/Mothers of Asthmatics, Inc.

Dolores Farr, R.N.
Healthy Babies Project

Jean G. Ford, M.D.
Harlem Hospital Center/Columbia University

Geraldine Mack
Healthy Babies Project

Guy S. Parcel, Ph.D.
University of Texas Health Science Center

Sydney Parker, Ph.D.
American College of Chest Physicians

Stanley J. Szefler, M.D.
National Jewish Center for Immunology and Respiratory Medicine

Sara L. Thier, M.P.H., C.H.E.S.
American Lung Association of Los Angeles County

Sandra R. Wilson, Ph.D.
American Institutes for Research

Eileen Zeller, M.P.H.
Asthma and Allergy Foundation of America

FOREWORD

The National Heart, Lung, and Blood Institute's (NHLBI) Division of Lung Diseases initiated a request for applications in 1989 for demonstration and education research programs to develop, implement, and evaluate interventions to reduce morbidity from asthma among African American and Hispanic children. Five projects were funded under this 5-year program, titled "Interventions for the Control of Asthma Among Black and Hispanic Children." The grantees are based at Howard University in Washington, D.C.; Columbia University in New York City; the University of Texas Health Science Center-San Antonio; Washington University in St. Louis, Missouri; and the University of New Mexico in Albuquerque.

The goals of this research effort were to develop model, replicable programs to reduce asthma morbidity, decrease inappropriate use of health care resources, and enhance the quality of life of African American and Hispanic children with asthma. Some interventions included efforts to increase the knowledge and change the behaviors of health care providers, as well as those of patients and their families and other groups within the community. Approaches to mobilize community resources to increase access to care, integrate patient education into medical care, and educate health professionals about asthma and its management were encouraged.

The approaches used by each of the five grantees in implementing their interventions varied widely. Based on their experiences, a number of insights have emerged about the design and evaluation of educational and management programs for asthma, strategies for recruiting patients and staff, and techniques and resources for community and professional education. These "lessons learned" are presented herein as practical tips for researchers, clinicians, and community health leaders and/or program planners. Where possible, the lessons are illustrated with specific examples from one or more of the five projects. However, some lessons were formulated through consensus among the investigators, who met three times in 1994 and 1995. The meetings also included representatives from the NHLBI and from the community.

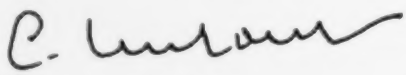
This document is intended as a mechanism for sharing the experiences of the five investigators in developing asthma management interventions; it does not contain study results. This information, along with detailed information about study methodology, is being published independently by each of the investigators. Some results are already available (see appendix II for a list of publications).

The NHLBI's National Asthma Education and Prevention Program (NAEPP) will disseminate this document. Established in 1989, the NAEPP is charged with transferring asthma research findings and scientific consensus to health professionals, patients, and the public for appropriate adaptation into their health care practices and individual lifestyles. The NAEPP's Coordinating Committee, which consists of 36 medical,

professional, and lay organizations that are involved in asthma education and management activities, provides effective channels for dissemination. One of the hallmarks of the NAEPP's broad-based activities conducted with coordinating committee members was publishing and widely disseminating the 1991 *Expert Panel Report: Guidelines for the Diagnosis and Management of Asthma*.

A continuing challenge in asthma control efforts is reaching minority populations. These populations have some of the highest rates of prevalence, emergency department use, and hospitalizations from asthma. The NAEPP's initiatives in this area have included conducting professional education sessions, distributing patient and public education materials written in English and Spanish, and conducting mass media campaigns for African American and Hispanic populations.

It is hoped that the information in this document will assist others in planning and implementing asthma management programs in various settings to help reduce morbidity and mortality from asthma in minority populations.



Claude Lenfant, M.D.
Director
National Heart, Lung, and Blood Institute

INTRODUCTION

BACKGROUND

Asthma is a major public health problem in children, especially children living in poverty. Children—those younger than age 18—have a 41 percent higher prevalence of asthma than the general population (7.2 versus 5.1 percent in 1993) (National Center for Health Statistics, 1994a). This means that nearly 5 million children in the United States have an illness that sometimes takes their breath away and limits their activities (National Center for Health Statistics, 1994a). In fact, children with asthma miss an estimated average of about 1 full week of school per year due to their illness, making asthma one of the most common reasons for school absences (Newacheck and Taylor, 1992).

Asthma is a major problem for African Americans. The prevalence of asthma in 1993 in African Americans under age 45 was about 23 percent higher than in whites (National Center for Health Statistics, 1994a). In 1992 the hospitalization rate for African Americans was more than 400 percent higher than the rate for whites (National Center for Health Statistics, 1994b), and the age-adjusted asthma mortality rate was 300 percent higher than for whites (Kochanek and Hudson, 1995). African American children have a 24 percent higher prevalence of asthma than white children, more limitation of their activity due to asthma, and more frequent hospitalizations from asthma (Weitzman et al., 1992). Lack of access to medical care, poverty, and delay in health-seeking behaviors are related to poor asthma outcomes in African Americans (Malveaux et al., 1993).

Some groups of Hispanic children are at risk for asthma-related problems because of language barriers, poverty, lack of access to medical care, and culturally based beliefs about health and illness. In addition, one subgroup within the Hispanic population, Puerto Ricans, has much higher rates of asthma and asthma mortality than others. During 1982-1984, prevalence of asthma in Puerto Rican children living in New York City was significantly higher, at 11.2 percent, than any other subpopulation studied to date (Carter-Pokras and Gergen, 1993). By contrast, the prevalence of asthma within Mexican American children was 2.7 percent, which is somewhat lower than the general population (Carter-Pokras and Gergen, 1993). The age-adjusted asthma mortality rate for Puerto Ricans in 1979-1981 was also much higher (4 per 100,000) than the rates for non-Hispanic whites (0.8 per 100,000) and Mexican Americans (0.5 per 100,000) (Carter-Pokras and Gergen, 1993).

The five minority asthma research projects discussed in this report were initiated with the goals of reducing asthma morbidity, decreasing inappropriate use of health care resources, and enhancing the quality of life of African American and Hispanic children with asthma.

HIGHLIGHTS OF PRACTICAL INSIGHTS

Many important insights have emerged from the development and implementation of the five projects. These insights or "lessons learned" are diverse, both in content and applicability, and have been organized into three sections: clinical notes, research notes, and public health notes. Individual lessons appear as bold statements that are, in most cases, followed by specific illustrations from the projects.

The clinical notes section contains insights in two general areas: patient education and management, and health professional education. The research notes section, which is designed with the novice researcher in mind, offers practical tips for all stages of research, from pilot studies to evaluation. The public health notes section covers a variety of issues relevant to the planning and implementation phases of minority asthma interventions.

The grantees selected varied widely in their approach to improving asthma care for minority children. Projects focused on an urban community, a school system, a rural medical care system, a residency training program, and a public health clinic system. From this diversity, some common insights emerged, such as:

1. Community-based and school programs need to ensure that primary care providers who are knowledgeable about asthma management provide appropriate asthma care. Education in the community or school alone is insufficient.
2. Clinicians should be trained to treat asthma by (1) building their skills in assessment and management, (2) providing an environment that supports implementation of current recommendations, and (3) encouraging clinicians to address one or two aspects of self-management at each visit. Traditional continuing medical education (CME) lectures are not enough to modify health care providers' behaviors.
3. Obtaining input from intended audiences (lay and professional) during program planning can maximize the appropriateness of intervention strategies. Focus groups, needs assessments, and pilot testing can result in better tailored programs.
4. Educational interventions should address attitudes, beliefs, behaviors, and skills of the intended group, not just knowledge. Ethnic and cultural appropriateness, reading level, and language barriers are important factors to consider.
5. Asthma patient education can be made simple and brief so that clinicians will implement it.
6. To tailor education to patients' needs, clinicians should assess patients' concerns about asthma and asthma medicines through open-ended questions and similar interview approaches.
7. Clinicians should discuss with parents the common problem that medications are often inappropriately discontinued when the child appears well.
8. Recognition should be provided to health care professionals and patients who work to improve asthma care or manage their asthma.
9. The number of patients retained in a study can be increased through an honest, sensitive, and understanding personal relationship with staff; convenience; incentives; and pleasant and rewarding experiences at followup visits.

These and other "lessons" will be elaborated upon later in this report. The next section briefly describes the five intervention studies from which these lessons were learned.

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Project Descriptions

An Intervention for Hispanic Children With Asthma

Principal Investigator: Pamela R. Wood, M.D., Associate Professor of Pediatrics, University of Texas Health Science Center (UTHSC)-San Antonio. *Co-Investigators:* Humberto Hidalgo, M.D., Department of Pediatrics, UTHSC; Thomas Prihoda, Ph.D., Department of Pathology, UTHSC; Megan Kromer, Ph.D., Instructional Development, UTHSC; William Hendricson, M.S., Instructional Development, UTHSC; Amelie Ramirez, Dr.P.H., Director, South Texas Health Research Center; Yolan Marinez, M.A., Department of Pathology, UTHSC. *Research Nurse:* Martha Selva, R.N., B.S.N., Department of Pediatrics, UTHSC. *Consultant:* Guy Parcel, Ph.D., School of Public Health, UTHSC-Houston.

The purpose of this study was to design, implement, and evaluate an intervention program for Hispanic children with asthma that included both physician and patient/family education components. The study questions were: (1) Will a physician education intervention result in increased physician knowledge and improved medical management for Hispanic children with asthma? (2) Will a focused educational intervention for Hispanic children with asthma and their families result in decreased morbidity and improved quality of life?

Prior to enrollment of patients, 44 pediatric resident physicians participated in an intervention, based on the NHLBI *Expert Panel Report: Guidelines for the Diagnosis and Management of Asthma*, that addressed the following areas: physician knowledge, information-processing skills, motivation, and the clinic environment. Components of the intervention were seminars on medical management, pocket cards with treatment algorithms, improved access to peak flow meters and spirometry, an interactive computer-based program, and individualized feedback. Physician knowledge was measured preintervention and postintervention using a 36-item computer-based test. In addition, participants were asked to rate their educational experience for 16 pediatric topics, including asthma. Finally, the effect of the physician intervention on specific physician behaviors was assessed through medical record review.

One hundred and forty-five children with asthma (79 percent Hispanic), ages 6 to 18 years, who receive care in a pediatric residents' continuity clinic, were enrolled. A research assistant interviewed parents and a research nurse interviewed children using standardized questionnaires to obtain information about health beliefs, reported health behaviors, knowledge and attitudes about asthma, morbidity, acculturation, and sociodemographic factors. A research nurse performed spirometry on each subject. Additional information was obtained by review of medical records and school attendance records. After baseline data were collected, patients were randomized into treatment and control groups. Treatment group patients and their families participated in the patient education program, which consisted of four separate 1-hour sessions: symptoms of asthma, causes of asthma, medications, and peak flow. The four sessions took place

over a 6-week period, and each session was conducted by a nurse educator. Culturally sensitive educational materials included both print (e.g., flip charts, take-home brochures) and videotape materials. The videotapes featured children from the clinic and highlighted what they did to successfully manage their asthma. All materials were developed in both English and Spanish. Followup data were obtained by interview, medical record review, and spirometry at 6, 12, 18, and 24 months following enrollment.

Intervention and control group children were compared for morbidity (number of emergency department [ED] visits, hospitalizations, school days missed, and days with impairment) and quality of life (impact on family and functional status), after controlling for confounding variables. Secondary data analysis will examine the effect of the intervention on knowledge, reported health behaviors, and postintervention spirometry. If effective, the physician education and patient education programs will serve as models for the implementation of similar programs in outpatient clinic settings that serve Hispanic children with asthma.

For additional information about the Texas project, contact Pamela R. Wood, M.D., Associate Professor of Pediatrics, The University of Texas Health Science Center at San Antonio, 7703 Floyd Curl Drive, San Antonio, TX 78284-7808; the telephone number is (210) 270-3971.

A Self-Management Educational Program for Hispanic Asthmatic Children

Principal Investigator: Shirley Murphy, M.D., Professor and Chair, Department of Pediatrics, University of New Mexico (UNM). *Co-Investigators:* Jean Hanson, R.N., M.N., Department of Pediatrics, UNM; Jodi Lapidus, M.S., Department of Pediatrics, UNM; Evelyn Oden, M.D., Medical Director, Children's Medical Services, Santa Fe, New Mexico.

The Children's Medical Services of New Mexico and the University of New Mexico Pediatric Pulmonary Program together designed and evaluated the impact of a new statewide comprehensive asthma program that provided medical care and coverage for medical costs for low-income children with moderately severe-to-severe asthma. The specific aim of this project was to determine whether comprehensive medical care (CMC) plus an educational asthma self-management program that included home visits by community lay educators (family educators) for rural Hispanic children and their families would have an impact on asthma morbidity, cost of asthma care, and family adaptation.

A randomized block design was used with random assignment of subjects by county of residence to experimental groups of (1) CMC, which was standard tertiary care with individual patient education, or (2) CMC-Plus, which was standard tertiary care combined with a structured, interactive group self-management education program, Open Airways/Respiro Abierto. In addition, CMC-Plus patients received in-home education and intervention from community-based Hispanic family educators trained in an empowerment model of family intervention, in-home support, and asthma education. Medical care for CMC and CMC-Plus was provided by the University of New Mexico School of Medicine Pediatric Pulmonary Division and in the local communities in collaboration with and transferring care back to the primary care/referring physicians.

The study tested the hypothesis that provision of CMC-Plus, as compared with CMC alone, would (1) reduce asthma morbidity in Hispanic children with asthma as indicated by decreased ED visits, hospitalizations, daily symptoms, and improved pulmonary function parameters; (2) reduce hospitalization and ED costs, but not decrease costs of providing primary asthma care; (3)

reduce family stress, as measured by the Parenting Stress Index and Impact on Family Scale; (4) enhance self-management and self-efficacy; and (5) enhance self-reported satisfaction with delivery of asthma-related health care services, in both the tertiary and primary care areas.

This project has important implications for other States that are considering providing funding for asthma care in that it will give insight into the most cost-effective way to provide care for rural children with asthma. The New Mexico Asthma Project will also provide valuable insights into the management of asthma in Hispanic and Native American populations.

For additional information about the New Mexico project, contact Jean Hanson, R.N., M.N., Department of Pediatrics, University of New Mexico School of Medicine, 2211 Lomas Boulevard, N.E., Albuquerque, NM 87131-5311; the telephone number is 505-277-3072.

A CHILDHOOD ASTHMA PROGRAM IN NEW YORK CITY HEALTH DEPARTMENT CLINICS

Principal Investigator: Robert B. Mellins, M.D., Professor of Pediatrics and Director, Pediatric Pulmonary Division, Columbia University College of Physicians & Surgeons (CU). *Co-Principal Investigator:* Katherine Lobach, M.D., Assistant Commissioner for Child and Adolescent Health, New York City Health Department, Director, Bureau of Child Health (BCH), and Clinical Professor of Pediatrics, Albert Einstein College of Medicine. *Co-Investigators:* David Evans, Ph.D., Assistant Professor of Public Health, Department of Pediatrics, CU; Moshe J. Levison, Ph.D., Associate Research Scientist, Department of Pediatrics, CU; Bruce Levin, Ph.D., Division of Biostatistics, School of Public Health, CU; Carmen Ramos-Bonoan, M.D., Deputy Director for Medical Affairs, BCH; Ilene Klein, M.F.A., Deputy Director for Operations, BCH; Caroline Donahue, R.N., M.A., Deputy Director for Nursing Affairs, BCH; Barry Zimmerman, Ph.D., Professor of Educational Psychology, City University of New York Graduate Center; Noreen M. Clark, Ph.D., Professor of Health Education and Health Behavior, University of Michigan School of Public Health; Lucille Rosenbluth, M.P.A., President, Medical and Health Research Association of New York City, Inc.; Deirdre Burke, M.P.H., Grants Management, Medical and Health Research Association of New York City, Inc.; Sandra Wiesemann, R.N., M.P.S., Project Coordinator, Medical and Health Research Association of New York City, Inc. *Consultant:* Marcia Pinkett-Heller, M.P.H., Department of Health Education, Jersey City State College.

Columbia University College of Physicians and Surgeons (CU) and the New York City Department of Health, Bureau of Child Health (BCH), the University of Michigan, City University of New York, and the Medical and Health Research Association of New York, Inc. (MHRA), cooperated in research to improve asthma care for minority children with asthma in New York City.

BCH operated 40 clinics that provided primary, preventive care to infants and children. More than 80 percent of the clinic patients were African American or Latino, and more than 90 percent were from minority groups. Registered children were assigned to their own pediatrician/nurse team and made regular scheduled visits, following Child/Teen Health Plan (C/THP) guidelines, for health assessment, diagnostic screening, and preventive care. The clinics also provided diagnosis, treatment, and followup of acute illnesses as well as referral and coordination by the child's clinic team for care by other providers. All visits and medications were provided free to patients, and for many parents without medical insurance, the BCH clinics were their only source of continuing pediatric care. Although the clinics have provided some care for acute episodes of asthma in the past, most children have been referred to other sources of care. At the onset of the study, fewer than 2 percent of the children enrolled in BCH clinics had a diagnosis of asthma in their clinic medical records, suggesting that there were many unidentified cases of asthma in the patient population.

The goal of the program was to improve the health status of inner-city African American and Latino children with asthma by providing them with a comprehensive system of preventive, continuing care that included up-to-date short- and long-term pharmacologic treatment, family health education, and community outreach. The study examined the hypothesis that training to create a comprehensive system of preventive, continuing care, including medical care, family health education, and community outreach, will (1) attract and retain families who have children with asthma in continuing care relationships in the BCH clinics; (2) improve staff confidence, therapeutic skill, and educational practices in the diagnosis and treatment of childhood asthma; and (3) improve the health status of patients and the quality of life of their families.

Among the key evaluation criteria for the hypothesis were, respectively: (1) increased numbers of patients identified with asthma and increased frequency of scheduled clinic visits for asthma care; (2) improved staff self-efficacy, increased dispensing of inhaled anti-inflammatory therapy for children with moderate-to-severe asthma, and better use of communications skills to identify patient concerns and convey appropriate educational messages; and (3) improved quality of life for families, reduction in morbidity (days with limited activity and night sleep disturbed by asthma symptoms), and decreased use of emergency health care services for asthma.

An experimental research design was used to evaluate the hypothesis and to determine whether the comprehensive system of preventive, continuing care could be institutionalized within the department of health. The project was carried out in two phases. In phase I, program faculty taught the clinic staff to provide comprehensive care for asthma and assessed the impact of this education on attracting families to continuity of care, changing staff practice behavior, and reducing morbidity. In phase II, the researchers made the comprehensive care system self-sustaining within the department of health by demonstrating that the same outcomes could be achieved when BCH physicians and nurse supervisors who were trained in phase I taught staff from the clinics not included in phase I.

For additional information about the New York project, contact Robert B. Mellins, M.D., Director, Pediatric Pulmonary Division, Department of Pediatrics, Columbia-Presbyterian Medical Center, Babies and Children's Hospital of New York, BHS 101, 3959 Broadway, New York, NY 10032, or David Evans, Ph.D., Assistant Professor of Pediatrics, Director, Asthma Research Program, Department of Pediatrics, Columbia-Presbyterian Medical Center, Babies and Children's Hospital of New York, BHN 807, 3959 Broadway, New York, NY 10032. Dr. Mellins can be reached at (212) 305-6551; Dr. Evans can be reached at (212) 305-6732.

Neighborhood Asthma Coalition

Principal Investigator: Edwin B. Fisher, Jr., Ph.D., Professor of Psychology and Medicine, Director, Center for Health Behavior Research, Washington University School of Medicine (WU). *Co-Principal Investigator:* Robert C. Strunk, M.D., Professor of Pediatrics, Director of Division of Allergy and Pulmonary Medicine, Department of Pediatrics, WU. *Project Director:* Linda Sussman, Ph.D., Research Instructor in Medicine, Research Associate in Anthropology, WU. *Investigators:* Cynthia L. Arfken, Ph.D., Research Assistant Professor of Medicine, WU; Janice Munro, M.Ed., Center for Health Behavior Research, Department of Medicine, WU; Roslyn K. Sykes, Ph.D., Visiting Research Assistant Professor of Medicine, Associate Professor, School of Nursing, Southern Illinois University at Edwardsville. *Collaborators:* Shirley Bascom; Lynn P. Hert, R.N., M.S.; Dorothy Harrison, M.S.W.; Sally Haywood, M.P.A., L.C.S.W.; and Nancy W. Owens, M.Ed., Grace Hill Neighborhood Services.

The Neighborhood Asthma Coalition was developed as a collaboration of Grace Hill Neighborhood Services in St. Louis and researchers at Washington University with the goal of reducing morbidity from asthma and increasing the extent to which children with asthma in low-income, African American neighborhoods lead full, active, normal lives. Other aims were to increase understanding of how a neighborhood, peer-based program may encourage better asthma care and quality of life among low-income, African American children with asthma as well as children from other minority or underserved groups.

Organized around Neighborhood Wellness Councils in each of four predominantly African American and low-income neighborhoods in St. Louis, the Neighborhood Asthma Coalition provided a wide range of activities and promotional events to raise neighborhood understanding of asthma and to engage children with asthma, their friends, and their families in educational activities stressing three key concepts: take asthma seriously; treat asthma symptoms with asthma medication; and when symptoms persist, get help. Additional educational events expanded on these key concepts and included attention to triggers, self-monitoring and self-management according to symptoms, and other curricular elements drawn from Open Airways. Neighborhood residents were trained and employed to assist with the program and, especially, to provide individualized basic asthma education and support to children with asthma and their caregivers. The Neighborhood Asthma Coalition established a wide range of programs and activities to pursue its goals. Highlights included training neighborhood residents to work as CASS workers ("Change Asthma through Social Support," a name chosen by Neighborhood Wellness Councils); asthma education activities carried out by parents in neighborhood schools and churches; and an innovative, neighborhood-based asthma summer camp that involved family members and friends as well as children with asthma themselves.

Practicing pediatricians serving the neighborhoods have participated in a Physicians' Advisory Board. This group has reviewed levels of care, especially regular, nonacute care available in the neighborhoods, and developed mutually agreed-upon standards for acute and regular asthma care. The board also serves as a point of contact between the neighborhood-based program and professionals. The emergency department staff of St. Louis Children's Hospital developed a "1...2...3...Plan" for asthma patients that emphasizes primary care followup of emergency visits as a way of prompting care through primary providers.

A quasi-experimental cohort design was used. Children from study neighborhoods were compared with children from sociodemographically comparable neighborhoods in St. Louis. The study tested the hypothesis that reductions in morbidity, increases in normal activities, and reductions in interference of asthma with daily life would be greater in experimental than in control neighborhoods. Outcome/evaluation criteria included utilization of emergency and routine asthma care (by provider records as well as parents' reports), symptoms of asthma (by parents' reports), asthma management practices (parents' reports), the extent to which children led normally active lives, and the extent to which asthma interfered with children's and families' routine activities.

For additional information about the St. Louis project, contact Edwin B. Fisher, Jr., Ph.D., Professor of Psychology and Medicine, Director, Center for Health Behavior Research, Washington University School of Medicine, Suite 6700, 4444 Forest Park Boulevard, St. Louis, MO 63108; the telephone number is (314) 286-1901.

Community Interventions for Minority Children With Asthma

Principal Investigator: Floyd J. Malveaux, M.D., Ph.D., Dean, College of Medicine, Howard University. *Co-Principal Investigator:* Cynthia S. Rand, Ph.D., Associate Professor of Medicine, The Johns Hopkins Asthma and Allergy Center. *Project Director:* Lera Thompson, M.S.P.H., Department of Microbiology, Howard University College of Medicine. *Investigators:* Arlene Butz, R.N., Sc.D., Associate Professor, Graduate Instructor of Nursing, School of Nursing, Johns Hopkins University (JHU); Peyton Eggleston, M.D., Professor of Pediatrics, Department of Pediatric Allergy and Immunology, School of Medicine, JHU; Karen Huss, R.N., D.N.Sc., Postdoctoral Research Fellow, School of Nursing, JHU.

This project was designed to test the effectiveness of a school-based asthma education intervention, a community health worker program, and a combination of the two in reducing the number of ED visits, hospitalizations, and days of restricted activity among African American children with asthma in Washington, D.C., and Baltimore, Maryland.

Forty-two elementary schools (21 in Washington and 21 in Baltimore) were selected from areas with predominately African American populations to participate in this project. The schools were randomized into one of four study groups. Two cities were chosen to implement this project because their size and proximity allowed the selection of a large enough sample to test a four-group design and because comparisons between outcomes in the two cities provided valuable data on the generalizability of this study's findings across cities and school districts.

The selected schools were randomized to either a control group, a school-based asthma education program, a community-based health worker program, or combined school-based education and community health worker programs. The two programs lasted 6 months.

In the asthma education intervention, a six-session curriculum was offered to elementary school children in grades 1 through 6. In this program children were taught by health educators trained by program staff. The program was designed to increase the child's as well as the family's knowledge about asthma and confidence and skills needed to manage asthma.

In the community health worker intervention, trained individuals from the community interacted with the families of the children enrolled in the program to assist in managing the child's asthma. The community health workers conducted home visits on a regular basis to offer advice on environmental issues and the development of an asthma action plan.

The primary aim of this study was to answer the following questions: (1) Can a school-based asthma education program set in the inner-city schools increase children's asthma knowledge and skills, increase self-efficacy, decrease school absenteeism, and increase academic performances among African American children? (2) Can a community-based health worker program increase preventive health care utilization, increase use of a primary care provider, decrease ED visits, decrease acute asthma episodes, and increase asthma knowledge and skills among African American children? (3) Can a combined intervention that addresses both asthma education and community health care access and utilization significantly improve on the separate interventions' ability to decrease asthma morbidity and related problems?

Outcome measures were utilization of emergency department, number of hospitalizations, asthma symptoms/asthma severity, academic performance, and asthma knowledge and skills.

For additional information about the Washington, D.C./Baltimore project, contact Lera Thompson, M.S.P.H., Project Director, Howard University College of Medicine, Department of Microbiology, Room 3010, 520 W Street, N.W., Washington, D.C. 20059; the telephone number is (202) 806-4322.

Practical Insights: Clinical Notes

Effective management of asthma requires regular visits to a physician, patient education, adherence to recommended medications, environmental control, and objective measurements of lung function. The researchers were faced with the challenge of getting both clinicians and patients to change the way they manage asthma. Lessons researchers learned in responding to this challenge are described in this section.

Key Lessons Learned

Patient Education and Management

- Patient education should include information about (1) the chronicity of asthma, (2) its potential to be fatal, (3) environmental control measures, (4) differences between medications, and (5) objective measures of lung function.
- A brief, simple approach can be useful, particularly in an emergency department.
- Patients should be provided with clear instructions for asthma self-management. A contract between doctor and patient can clarify expectations.
- Clinicians should respect the cultural beliefs of minority patients and design interventions that are culturally appropriate.
- Clinicians should recognize and address parents' reluctance to provide daily or frequent medication to their children if their children appear to be well.

Education for Health Professionals

- Input should be sought from health professionals targeted for education.
- Convenient, user-friendly approaches enhance health professional education. Traditional lectures are insufficient.
- Graphic presentation of treatment plans, such as through flow charts, are useful in teaching asthma management to health professionals.
- Strong administrative and supervisory staff support is important in interventions to improve the delivery of asthma care in health systems.
- An advisory board of community health professionals can help promote continuity of care.

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Patient Education and Management

Patient education can be brief and simple. A few key points should be emphasized:

- Patient education should include simple explanations of the chronicity of asthma.
- Asthma education should raise expectations of a normal, active life but also point out that asthma episodes can be fatal if the disease is not kept under control.
- Patients should be encouraged to implement environmental control measures, such as avoiding exposure to tobacco smoke in the home or car, dust control, and having no warm-blooded pets in the home.

Patient education can be brief and simple so that clinicians will implement it.

All projects found that cigarette smoking was more prevalent than expected among parents of asthma patients. Fifty percent of patients were exposed to smoking at home. During every visit, patients should be asked who is smoking and where. People should be encouraged not to smoke in the car or at home. The video used in the Texas project, "Cigarette Smoking and Asthma: A Bad Combination," was useful in communicating the effects of smoking on asthma.

Community health workers visiting the home had an impact on the home environment in Washington, D.C./Baltimore. The workers identified environmental risks such as carpeting (which often cannot be removed because the family either lives in rental property or cannot afford to have it removed), cockroach infestation, mold, and rodents.

It is important to inquire about pets. Sometimes asking the names of the patients' pets will elicit information.

- Patients should be educated about asthma medications by (1) teaching them to distinguish medications used to treat chronic asthma (anti-inflammatory medications) from those used to treat acute episodes (short-acting inhaled $beta_2$-agonists) and (2) clarifying and repeating times, doses, and amounts of all medications (right medications, right use, including use of a metered-dose inhaler).

  Researchers in the New Mexico project described medications as treating the quiet (chronic) parts of asthma (i.e., inhaled steroids, nedocromil, cromolyn) and the noisy parts of asthma (inhaled $beta_2$-agonists).* The Texas project described these medications as ones that *prevent* symptoms and ones that *treat* symptoms.

  Other strategies to help patients understand the difference between bronchodilator and anti-inflammatory medicines include (1) having patients bring all medicines to each visit, (2) using special labeling, and (3) having patients describe their medication use by asking them when they take medications during their daily routine (not simply how many times a day they use the medicine).

- Patients of appropriate age (at least age 5) and ability should be taught how to use a peak flow meter and how to monitor symptoms.

(See public health notes section, page 34, for a description of the simplified messages used in the St. Louis community program.)

Culturally and linguistically appropriate approaches to patient education are critical. Asking a few open-ended questions to assess the patient's concerns about asthma and asthma medicines can help the clinician to

* Concept adapted from video "Wheeze World," Allergy and Asthma Network/Mothers of Asthmatics, Inc.

tailor health education and the therapeutic program to the needs of the patient.

The Washington, D.C./Baltimore researchers found that the term "triggers" connoted images of violence for some children. Substituting the phrase "things that start asthma attacks" for "triggers" helped avoid misinterpretation. The Texas researchers used the phrase "causes of asthma problems" to avoid misunderstanding of the term "triggers."

Clinicians should be aware that some cultural beliefs may promote the use of "alternative medicine." New Mexico researchers found that 30 percent of patients used alternative therapies for asthma such as chihuahua dogs, curanderos, acupuncture, and herbal preparations. The New Mexico project recommended inquiring about alternative treatments and not invalidating the remedies. Texas and New Mexico researchers found that it is important to negotiate care and the use of alternative treatments.

In the New York project, participation of staff members who spoke the language of the clinic population was extremely important in understanding the reasons behind nonadherence to recommended protocols.

It is important for clinicians to provide patients with clear, written, understandable instructions on asthma management at home. A contract signed by the doctor and patient can clarify expectations.

In New York, written forms for providing easily understood long-term treatment plans were used and appreciated by both physicians and patients (see appendix III). The form enables the physician to outline a long-term treatment plan that helps patients to make adjustments as symptoms change. Treatment plans placed on the refrigerator door remind families of the specific recommendations by the physician and when to call the clinic or go to the emergency department for immediate care. If good control is maintained, the treatment plan provides recommendations for reducing medications.

Written instructions are helpful to patients.

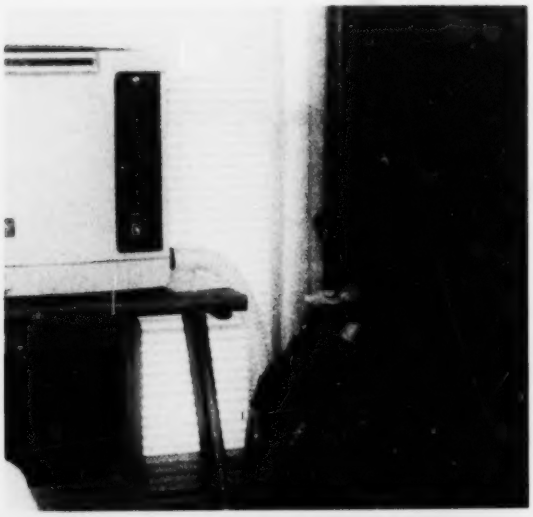
The New Mexico researchers showed that patients who had a peak flow meter, clear instructions for its use, and an asthma action plan (see appendix III) were able to manage their asthma effectively, despite living far from medical care services.

Initially, however, not all patients took the New Mexico program seriously. Children's Medical Services staff had patients sign a contract that they would perform all the management methods recommended by the medical staff. It was especially useful for patients who had not been taking their medications. The researchers also found contracts useful for dealing with smoking in the home.

Objective measures (peak expiratory flow rate [PEFR] and/or spirometry) are valuable for monitoring the management of asthma and can be used in a variety of ways with children 5 years of age or older.

The more severe the asthma, the more likely the patients will use a peak flow meter regularly. However, it is often unrealistic to expect patients to do peak flow monitoring every day of their life.

Patients can use PEFR episodically to assess acute symptoms. Those who live a great distance from



Spirometry is a valuable tool for monitoring asthma management.

care can provide their PEFR measurement to the physician over the telephone, which will enable the physician to assess the severity of the episode. In New Mexico, peak flow measurements were found to be invaluable for communicating to the physician the severity of the episode and the response to medications.

In addition to episodic measurements, patients in New Mexico were asked to monitor PEFR for 2 weeks before coming to the clinic. They were called and given reminders on fluorescent self-stick notes to remind them to carry out this task. This 2-week monitoring period gave a better picture of the patients' asthma than one measure of lung function at the clinic.

New Mexico presented pulmonary function test numbers to patients like grades in school to indicate what was a "good," "bad," or passing number (e.g., 60 percent=F, 80 percent=B). Flow volume loops were shown to patients so they could have a visual indication of their asthma severity. The Texas researchers used a simpler approach and told patients that a FEV_1 under 80 percent is a sign of trouble.

Clinicians in the New Mexico project performed spirometry on every child 6 years of age or older at every clinic visit. As a result, medication could be adjusted accordingly. In addition, the spirometry readings were an important source of feedback to families.

Clinicians should inquire about patients' use of over-the-counter medications.

Washington, D.C./Baltimore and St. Louis researchers found that a high percentage of patients used over-the-counter cough medicines and decongestants to treat asthma. New Mexico researchers found that many asthma patients used Primatine Mist.

It is important that patients be able to afford or be provided with medications and equipment for acute asthma management at home.

In New York, a loaner program for nebulizers was created for families who could not afford to purchase them. The patients returned the equipment in good condition. In New Mexico, because of the distances from health care, everyone was provided a nebulizer and prednisone for handling emergency situations.

Even though asthma is a chronic disease, many parents discontinue giving medications when the child appears well.

The Washington, D.C./Baltimore researchers found that many children were on inappropriate regimens and that their families were not knowledgeable about asthma prevention. Approximately half of the children were responsible for their own medication (i.e., parents did not supervise the taking of medicine). A large percentage of the families used the emergency department for primary asthma care; thus, ongoing asthma care was problematic. Many parents thought it was unnecessary to give medicine to children who were not symptomatic. This belief may be a major barrier to the continued use of appropriate medication.

Ways to help parents continue to give the medications include frequent contact (e.g., telephone calls, home visits), objective monitoring (PEFR and symptom diary), and repetition of educational messages. In St. Louis, for example, trained neighborhood residents maintained contact with parents to encourage ongoing adherence and regular care, remind them of program events and opportunities, and provide support and assistance in dealing with asthma and other problems in their lives.

In the New York program, children on daily medication were instructed to maintain the program for a minimum of 2 months and preferably until the child had no chest complications when he or she had had several colds.

Patients who work to manage their asthma should be recognized for their efforts.

In New Mexico, graduation certificates for completing the 2-year project were given to patients to affirm their progress in managing their asthma. The St. Louis project included a graduation program with certificates and T-shirts bearing the program logo on the last day of asthma summer camp.

Strategies to maximize the efficiency of asthma education and care are beneficial for primary care physicians and clinics.

In some of the New York study clinics, half-day sessions devoted to patients with asthma helped the staff treat asthma more effectively and efficiently. This approach also enabled educational sessions to be conducted for families and other caregivers using the Open Airways program.

Primary care physicians in rural New Mexico also indicated that their staff was too busy to conduct lengthy patient education. The physicians wanted a few important points that their staff could emphasize and reinforce, perhaps in a flash-card format.

Rather than providing extensive education, emergency care providers may review selected key points and encourage patients to obtain regular outpatient care.

Researchers in St. Louis recognized that time constraints on personnel and the understandable distress of many patients and families can block effective asthma education in the emergency department. A solution to this problem was a simple plan known as the "1...2...3 Plan" (see appendix III). This plan lists specific steps for taking preventive and rescue medication, steps for responding to warning signs of an asthma episode, and encouragement to secure an appointment for regular followup care within 72 hours of the emergency department visit.

Rather than providing extensive education, emergency care providers may review selected key points and encourage patients to obtain regular outpatient care.

EDUCATION FOR HEALTH PROFESSIONALS

Educational interventions for health care providers should be based on input from the providers.

The Texas researchers obtained input from the targeted physicians on their perceived needs and preferred instructional methods through several focus groups. Investigators solicited input and modified the program on an ongoing basis as participants advanced in knowledge and as new participants entered the program.

The New York investigators assessed the Bureau of Child Health clinic staff's perceptions about the need for changes in asthma care and the feasibility of implementing changes. The researchers found that many providers viewed

asthma as an episodic disease requiring treatment of symptoms as they occurred. The providers were reluctant to accept the concept of asthma as a chronic disease that requires preventive care, and they feared that doing so would result in unmanageable increases in patient load. To respond to these concerns, the investigators focused on strategies to (1) help staff link the goals of continuing care for asthma to the bureau's preventive care mission; (2) help staff identify and resolve organizational problems that blocked acceptance of the new approach to asthma care; and (3) involve all staff members in planning how to implement the program so that the staff of each clinic would learn to function as a team and develop a sense of ownership of the asthma program.

Traditional continuing medical education (CME) lectures are not enough to modify health care providers' behaviors.

The best approach to training clinicians to treat asthma involves building skills in assessment and management, providing an environment that supports implementation of current recommendations (e.g., access to peak flow meters and to personnel who can assist in training families), and encouraging clinicians to address one or two aspects of self-management at each visit, rather than attempting to change behaviors all at once. User-friendly, convenient education approaches can also help. Traditional continuing medical education (CME) lectures are not enough to modify health care providers' behaviors.

The Texas project's educational intervention for physicians included three hands-on seminars that covered the following content areas: spirometry and peak flow, stepwise use of medications, and symptom recognition and elimination of triggers. During the spirometry and peak flow session, physicians actually performed spirometry and then interpreted the results. They calculated their own predicted peak flow value and had an opportunity to practice using peak flow meters. During the medications seminar, they had an opportunity to observe and then practice the correct technique for using a metered-dose inhaler, and they acquired experience handling several different spacer devices.

An effective computer-based education program was developed in the Texas project; however, in conducting their physician education program, the Texas researchers found that it was essential to schedule specific time blocks for physicians to receive instruction. Physicians were unlikely to complete certain aspects of the program (such as computer-based instruction) independently unless specific times had been scheduled for them to do so.

New Mexico researchers believed one of their most effective strategies for physician education was collaborative evaluation of patients by primary care physicians and program specialists. This was done in the office of the private practitioners because these physicians were too busy to go to the researchers' Albuquerque clinic to see patients and could not afford a whole day out of their offices. Older as well as younger physicians were willing to participate and adapt their asthma management practices.

It is also important to provide education for more than just physicians; other clinical and office staff must also know what to emphasize during asthma education sessions and can reinforce the recommendations and instructions to families. New York investigators found that patients were sometimes more comfortable discussing problems and seeking help from nonprofessional clinic staff (e.g., entry clerks or lab technicians) than they were with doctors and nurses. For this reason, the entire clinic staff took part in the intervention training.

Simplified and convenient prompts and reference material (e.g., flow charts) are particularly useful educational tools for health care providers.

Physicians targeted in the Texas project indicated that pocket cards and hands-on seminars were the most beneficial components of their asthma education. The Washington, D.C./Baltimore investigators found tear-out action plans and medication sheets to be useful resources for practitioners.

Just providing the NAEPP's *Expert Panel Report: Guidelines for the Diagnosis and Management of Asthma* is not enough. The guidelines need to be simplified and instruction provided (for example, as in the flow sheets in the NHLBI/WHO workshop practical guide; see appendix III).

Physicians may not be receptive to using forms to document patients' visits.

Although printed history and physical examination forms were helpful in the New Mexico project (see appendix III), the New York investigators found that medical record forms they devised to guide physicians through the process of initial and continuing visits for asthma were not enthusiastically received. Most of the physicians preferred to use a blank form for recording notes.

Health care professionals should be recruited and trained to teach other providers about asthma management.

Clinic staff members who had received training from the New York program staff were able to do an excellent job of training the staff of other clinics in the Bureau of Child Health. Clinic staff members who served as trainers needed considerable support initially from the investigators in learning to deliver the program. They were somewhat anxious about being able to successfully carry out the training program with their peers, and they did not initially realize the degree of teamwork and rehearsal necessary to carry out the program. With experience, however, the trained staff members became confident and skilled educators, and their teaching of the program was received enthusiastically.

Interventions to improve the delivery of asthma care in health systems are enhanced by strong administrative and supervisory staff support.

Incentives, including the provision of CME credits for physicians, were helpful in getting physicians to participate in the New York program. St. Louis gave CME credits for physicians and continuing education units for nurses who attended their yearly asthma conference.

Recognition should be provided to health care professionals and other workers who strive to improve asthma care.

In New York, a graduation ceremony at which senior members of the health department were present was held to award individual and clinicwide certificates for completion of the program. This helped to increase morale and reinforce active participation by the staff.

Interventions to improve the delivery of asthma care in health systems are enhanced by strong administrative and supervisory staff support.

The presence of influential administrative and supervisory staff at all of the intervention sessions in the New York program emphasized the importance of the program to the Bureau of Child Health and increased the clinic staff members' motivation to initiate the program in their clinics. Key staff members were instrumen-

tal in helping clinicians link the goals of continuing care for asthma to the bureau's mission of providing preventive pediatric care. Having administrators present also helped resolve organizational issues that blocked acceptance of the new approach to asthma care, such as concerns about keeping up with scheduled appointments and coping with large numbers of new patients.

The Texas investigators found that starting their physician education program with supervising faculty and fellows allowed a consistent approach to patient management at all provider levels and enabled consistent information and feedback to be given to residents in clinics.

A community health professionals advisory board can be useful in promoting continuity of effective asthma care.

The St. Louis investigators recruited a group of leading neighborhood health care providers to function as a Physicians' Advisory Board. The board members met regularly to identify problems and ways to improve the provision of asthma care within specific neighborhoods. They reviewed data generated by the research project as a nonthreatening, nonjudgmental approach to identifying problems for discussions. A physician's guide, which included patient educational materials for use in outpatient settings, was developed with input from the Advisory Board and based on educational materials from the Childhood Asthma Management Program. In addition, an annual joint community professional asthma conference, organized by the board in collaboration with program staff, volunteers, and children with asthma and their parents, provided education for physicians and other professionals, as well as parents, children, and neighborhood volunteers and staff.

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Practical Insights: Research Notes

The investigators from the five projects identified key points that would be useful in planning intervention research studies for minority populations. Practical tips for developing demonstration and education research projects are described below.

Pilot Studies

Prior to beginning an intervention, it is advisable to conduct a needs assessment (e.g., focus groups) and pilot studies to address questions related to recruitment strategies, assessment measures, design of the intervention, and followup strategies. Dealing with these issues in advance can save time and resources during the intervention.

The Washington, D.C./Baltimore researchers piloted all phases of their project, including questionnaires, curricula, and forms used by the community health workers. Investing time and attention in a needs assessment and pilot phase, for example, allowed the A+ Asthma Club to be designed from the beginning with consideration for logistical constraints (e.g., not having chalk boards or other equipment in the classroom). The needs assessment also indicated that separate sessions for children in the upper and lower elementary grades were necessary. Focus groups confirmed the need to replace traditional asthma education jargon with vocabulary more appropriate to the intended audience.

In pilot studies, the New York investigators found that a traditional continuing medical education program in current concepts of asthma therapy and patient education was not effective by itself in changing clinic staff health behavior. The pilot studies identified several barriers to the implementation of the program: staff concerns (e.g., fears that they would be overwhelmed by the influx of patients with asthma), misperceptions about the pathogenesis and treatment of asthma, difficulties in accommodating the preventive aspects of asthma control, and deficits in the ability to communicate effectively with patients and families. The intervention was then revised to involve all staff members in planning how to implement the intervention and to use techniques that fostered teamwork among the individual clinic staff members.

The New Mexico project pilot-tested several different education programs, which was helpful in selecting an appropriate format. Data collection instruments were also extensively pilot-tested and refined.

Texas investigators had the opportunity to test methods of identifying and recruiting eligible study participants during a previous study of morbidity in Hispanic children with asthma. They found that patient registries could be used to identify potentially eligible subjects and that further screening and recruitment could be done by telephone or in face to face interviews. In addition, it was found that several telephone contact numbers were needed to be able to track participants over time.

Key Lessons Learned

Participant Recruitment/Retention

- Recruitment can be conducted through a wide variety of sites; each has advantages and limitations.
- Screening questionnaires are effective recruitment tools.
- Participant recruitment and retention are facilitated by incentives, including convenience and comfort factors.
- The informed consent process and followup efforts can be challenging and time consuming.
- Understanding an organization's structure is important for accessing participants through the organization.

Questionnaires and Assessment Measures

- Language, literacy, culture, and conceptual relevance should be considered when developing questionnaires.
- Morbidity data are a more useful basis for recruitment than severity measures.
- Outcome measures should assess not only morbidity but also quality of life, social support, and family functioning.
- Medication use and technique should be evaluated.
- Other sources of data may not correlate with study data.

Intervention Design, Delivery, and Evaluation

- A steering committee can be useful for improving study design and execution.
- Maintaining a pure control group in a community intervention may not be possible.
- Assessing staff attitudes and receptivity in advance allows for a more appropriately tailored intervention.
- Evaluation of asthma management programs should be multidimensional.
- Power analyses should take into consideration the likelihood of missing data.

Patient/Participant Identification and Recruitment

A variety of sites can be used for identifying and recruiting participants. (See table 1.)

Screening questionnaires can be an effective tool for identification and recruitment of participants.

The New York investigators developed a screening questionnaire that was used at the Bureau of Child Health clinics to identify children with asthma (see appendix III). The reception clerks or other workers at the clinics were taught to hand out the questionnaire at specific age intervals for children who came in for routine visits. The children's parents would complete the

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Table 1

RECRUITMENT SITES

Recruitment Site	Rationale	Limitations
Schools	■ Concentrated source of potential participants ■ Broad-based sample of children ■ "Captive audience" for direct intervention ■ Generally receptive to asthma education interventions	■ May impose constraints upon researchers; flexibility is required
Hospital-Affiliated Clinics and Inpatient Facilities	■ Useful for reaching minority patients ■ Participants can be identified through easily accessible patient registries	■ Diagnosis and study eligibility must be verified ■ Patient contact lists may not be accurate
Community Physicians	■ Potentially important source of patient referrals	■ Physicians are not always willing to participate in interventions[1]
Emergency Departments	■ Useful for identifying and reaching patients with poorly controlled asthma, minority patients, low-income patients, and those without a primary source of care	■ Contacting and recruiting patients with social and economic problems may be challenging[2]
State Agencies	■ Useful resource for identifying study participants	■ May impose some constraints upon researchers[3]
Public Health Clinics	■ Source of patients with undiagnosed asthma and patients without a regular source of primary care ■ Interventions can bring about broad changes in medical practices	■ Budgetary constraints and local bureaucratic changes have the potential to create roadblocks for researchers

[1] Community physicians initially resisted participating in the New Mexico program because they did not completely understand the program and feared losing patients to it. This slowed recruitment considerably. Concerns about time and space limitations, confidentiality issues, and possible chart audits are other potential sources of physicians' reluctance to refer patients for research.

[2] Researchers in the St. Louis project were able to contact 74 percent of patients with asthma identified from a list of children admitted to St. Louis Children's Hospital Emergency Department. The children's parents or guardians were contacted by telephone and/or letter with followup by telephone to determine their interest in participating in the study. Several callbacks per family were required to recruit each patient. Changes in phone numbers and incorrect phone numbers also reduced the contact rate. However, once contacted, of those eligible, 93 percent agreed to participate in the intervention. Of the first 103 children identified and recruited for the St. Louis study, 77 had had no regular asthma care in the previous year.

[3] The New Mexico project had patients identified by Children's Medical Services, a State agency for children with chronic medical conditions. This proved a viable method of identifying patients, but budgetary considerations limited uniform and timely enrollment in some areas of the State. In addition, the methodology of the study was influenced to some degree by the involvement with Children's Medical Services.

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questionnaire, which would provide the physician with some history and enough information to initiate an inquiry about asthma symptoms. All clinic personnel also received basic training about asthma. They were encouraged to feel free to give a screening form at any time if they suspected a child might have asthma and to communicate their observations to the physician either verbally or by writing observed symptoms on the screening form. A copy of each screening form was set aside and collected every 4 to 6 weeks, tallied, and a report of findings sent to the regional supervisors of the clinics. Regional supervisors could use these data to monitor participation in the asthma program.

Based on information from the screening form and subsequent questions to the family, physicians who suspected that a child might have asthma then would invite the family to enter the asthma program at the clinic in which the child ordinarily received care. The proportion of patients with asthma seen in the targeted BCH clinics nearly tripled by the second followup year as a result of the questionnaire.

Face-to-face contact can be an important aspect of recruitment.

The Texas investigators felt that a face-to-face, one-on-one approach with bilingual staff members who understood Hispanic culture was a crucial component for successful recruitment of Hispanic participants.

Obtaining consent from potential participants can be time consuming and challenging. The use of material incentives may improve the efficiency of recruitment.

In the Washington, D.C./Baltimore project, project descriptions and consent forms were mailed to parents of children identified as potential participants. In many cases, multiple mailings and followup telephone calls were needed before the consent forms were returned. A tremendous amount of time was invested in obtaining consent forms.

Incentives can facilitate participant recruitment.

In St. Louis, evaluation interviews were by telephone, but signatures were required for medical chart release forms, and Social Security numbers were required for payment after completion of interviews. These items were on a single form, and most people returned release forms quickly since payment was contingent upon returning them.

Incentives that were used with success in the five projects included:

- Monetary reimbursements (for example, $15 for baseline and final interviews and $10 for quarterly followup interviews)
- Bus tokens, cab vouchers, travel money
- Toys, photographs (taken at first visit and given at followup visit), tote bags, T-shirts, refrigerator magnets, key chains, bumper stickers, asthma watches
- Strategies to make the educational experience fun (such as calling a program a "club")
- Free meals
- Educational materials, training, free medical care and medication, peak flow meters, mattress covers

It is crucial to understand the hierarchy of a given organization and to know which key players, at all organizational levels, control and facilitate access to study participants and records.

With some organizations, permission to access participants must be granted by individuals in high administrative positions (a so-called "top-down" approach). With others, people with lesser positions may be instrumental in accessing participants ("bottom-up"). For example, school nurses and/or chapter I workers (in schools receiving Federal funding) can be avenues for identifying children with asthma. Secretaries in schools and parent liaisons are also potential sources.

In order to obtain school records of student attendance, Texas investigators had to contact and negotiate with 12 different independent school districts, as well as several private schools. Each district had specific requirements for approval of research studies and for the manner in which data could be requested and obtained. In general, schools were very receptive to efforts to improve the life of children with asthma but were concerned that the research study would require additional effort and time to be expended by their staff members. Only one private school refused to provide attendance data after consent had been obtained from the subject's parents.

The Washington, D.C./Baltimore project invested over 9 months in contacting officials in the school system. Superintendents, research reviewers, health professionals, and principals of schools were among those contacted for permission to conduct the research.

In New York, the leadership at the department of health was aware that many children with asthma within the families being followed by their clinics were going to emergency departments for crisis care rather than receiving preventive care at the clinics. Because the BCH clinics were centrally administered, the leadership could and did facilitate patient recruitment into the program.

PATIENT/PARTICIPANT RETENTION

Factors that can help maintain patients' participation include an honest, sensitive, and understanding personal relationship with staff; convenience; incentives; and pleasant and rewarding experiences at the followup visits. In addition, obtaining several contact names and telephone numbers at enrollment increases the likelihood of finding participants who do not come to appointments. The use of a professional survey research firm also can be effective in following up with participants.

The Texas investigators found that it was important to personalize interactions with patients' families by learning the names of family members and showing genuine concern for them, often merely by inquiring about them. Staff members took the time to chat with families, even if they did not have an appointment, and made positive comments about the child and the family whenever possible. It was important to constantly encourage families and to be patient with them. Bilingual staff members who were competent in dealing with Hispanic families also enhanced communication and facilitated retention efforts in the Texas project.

Factors that can help maintain patients' participation include an honest, sensitive, and understanding personal relationship with staff; convenience; incentives; and pleasant and rewarding experiences at the followup visits.

The St. Louis staff also strove to establish rapport with patients by being knowledgeable about asthma and pediatrics, having an understanding of urban living and its effects on children and their parents or guardians, using simple and appropriate levels of communication, and working hard to be perceived as honest and trustwor-

Honest, sensitive communication with patients can help retain them in a study.

thy. Both the interviewers and educational staff emphasized the confidentiality of information and that they were not "checking up on" or interested in "reporting" parents. Also, a $10 incentive was offered for each quarterly interview. Many participants looked forward to the quarterly interviews (the response rate was 85 percent) and even contacted staff members between interviews for information or to report developments in their children's asthma.

The New Mexico investigators initially tried to conduct their research program exclusively through a clinic in Albuquerque. The rurally located patients found travelling to Albuquerque for followup visits to be the most difficult part of the program. Once outreach clinics were established around the State in the families' own communities, virtually 100 percent of patients kept their scheduled appointments. The researchers tried to provide a comfortable setting with snacks and beverages. Although the families appreciated this gesture, it was difficult to implement on a continual basis because of space and setting limitations.

Changing telephone numbers and interruptions in telephone service for low-income participants can lead to challenges in followup. This situation resulted in the New York investigators' obtaining followup interviews for only 50 percent of patients interviewed during the baseline year. New Mexico researchers also found disconnected telephones and returned mail a frequent and time-consuming problem. Children's Medical Services caseworkers were helpful in tracking patients.

The St. Louis investigators contacted those whose telephones had been disconnected by sending postcards requesting that participants call for their quarterly interview. The frequency of the interviews helped the researchers maintain current addresses and telephone numbers. Periodic checking of hospital records also provided updated information for some participants.

The Washington, D.C./Baltimore investigators used a professional survey firm to conduct telephone interviews. Although the initial expense was high (between $50 and $70 per followup), the strategy was cost-effective in the long term. Four hundred participants could be interviewed within 3 to 4 weeks, with an 84 percent completion rate. In addition, the quality and completeness of the survey were ensured through internal quality control checks at the survey firm.

Participants who could not be reached by telephone in the Washington, D.C./ Baltimore project were sent a note with a toll-free telephone number and the promise of $20 for calling in for followup.

STAFFING

(See public health notes section for a full discussion of staffing.)

QUESTIONNAIRES AND ASSESSMENT MEASURES

Issues related to language, literacy, culture, and conceptual relevance should be considered when developing and selecting questionnaires and other assessments.

Not only word choice but phrasing and format can affect the ability of a participant to understand a questionnaire and its relevance. In the Washington, D.C./Baltimore project, for example, respondents were confused by questions regarding the likelihood that a particular situation would occur (e.g., 100 percent likely, 50 percent likely). Avoiding jargon was essential. For example, the phrase "at home" was used instead of "at your home" and the "room where you sleep" instead of "your bedroom." In the New Mexico project, participants did not understand the relevance of a Parenting Stress Index Questionnaire and consequently were reluctant to complete it.

Outcome measures for asthma interventions should include, in addition to the usual measures, assessments of quality of life, social support, and family functioning.

Measures of social support in the community were shown to be important predictors of health care utilization in some of the projects. In St. Louis, for example, parents were asked to estimate the number of family members and friends they "feel at ease with and can talk to about personal matters" and "can call on when you need a favor." Those who indicated relatively few confidants—that is, those who were quite socially isolated—reported that their children had more frequent asthma symptoms and emergency visits.

In the Texas study, several standardized questionnaires as well as specific questions developed by the investigators were used to assess a broad range of outcomes related to quality of life, morbidity, and the impact of the illness on the child's family.

(Detailed information about asthma outcome measures is available in the National Heart, Lung, and Blood Institute asthma outcome measures workshop report [National Heart, Lung, and Blood Institute, 1994].)

It is important to collect information about patterns of actual medication use and to assess self-medication technique.

Recording prescribed drug regimens is not sufficient to gauge medication use. Assessments of how participants in the Washington, D.C./Baltimore project recorded medication use indicated that bronchodilators prescribed to be used as needed were, in some cases, being taken daily, whereas anti-inflammatories, which had no immediate benefit, were not necessarily taken daily as they should have been.

It may be helpful to avoid using the term "asthma" when recruiting patients.

Parents who are not aware, or do not believe, that their children have asthma may not see a need for intervention and may, therefore, keep their children out of a potentially beneficial study. Others may be frightened by the term. Broad eligibility definitions, such as recurrent cough or wheezing, restricted activity, or awakening at night, can maximize recruitment of eligible participants. In New York, the use of the screening questionnaire was helpful to the clinicians in determining which patients needed followup appointments to discuss the problems of asthma more fully with parents or caregivers.

It is important to collect information about patterns of actual medication use and to assess self-medication technique.

There may be a poor correlation between morbidity data collected through the study and data from other sources. In some cases, it may be difficult to determine which data are correct.

In the Washington, D.C./Baltimore, St. Louis, and Texas projects, parental reports of emergency department use were higher than those indicated in hospital records. Whether this disparity was because of poor parental recall or inaccurate hospital records could not be determined. In St. Louis, concurrence of parental recall and medical charts for outpatient physician visits was particularly low.

Obtaining data from school on days absent due to asthma is challenging.

The investigators' attempts to obtain this information were unsuccessful. Many schools were able to provide data on the total number of days absent, but not a total breakdown by the reason for the absence.

Objective measures of lung function should be used only after weighing the potential costs, including burden to patients, against the potential benefits of the assessment. The age of the patients and their ability to perform tests of lung function also are important factors to consider.

Basing patient recruitment on morbidity data (frequency of symptoms, intensity of symptoms, and frequency of urgent care visits and hospitalizations) may be a preferable alternative to severity measures, which are more difficult to define.

When translating assessment instruments from English to other languages, reliability and validity must be documented again in the research population.

DESIGN AND ASSESSMENT OF INTERVENTION DELIVERY

Quality control and monitoring of program implementation according to standards are important and can be conducted in a variety of ways.

In the Washington, D.C./Baltimore project, observers were used to monitor the quality of instructors. The researchers also found it helpful to obtain feedback directly after an educational session with children to ensure that incorrect information was not being taught.

The New York project developed a training manual to help standardize the delivery of the program by both the investigators and the BCH staff members who were trained to deliver the program in the second phase of the study. The strategy resulted in a stronger, more consistent intervention. The program delivery team members monitored each other's performance during each session, enabling the team to make corrections as needed during the session to respond to particular needs and to stick to the overall plan.

In the St. Louis program, staff members observed neighborhood residents implementing curricula. Frequent in-service training and review of program progress and problems served to encourage instruction according to standards.

A steering committee can be useful in improving study design and execution.

The New York investigators created a steering committee that included the investigators from Columbia University, the Bureau of Child Health, and the Medical and Health Research Association of New York, Inc., as well as a supervisor from each of BCH's five regional divisions. Periodic (e.g., monthly) meetings of representatives from all parts of the program were useful to recognize problems early and to work out solutions quickly. A nurse-educator made monthly visits to each clinic to talk with the staff, reinforce program

messages, and troubleshoot. She brought her findings to the steering committee, which became the principal decisionmaking body for the study. Decisions were made as to how the BCH supervisors could more effectively reinforce the intervention in the field based on the information brought to the committee by the nurse-educator, the BCH supervisors, or administrators and on information from database management reports.

In St. Louis, a "nuts 'n bolts" committee of researchers and community staff members, including field workers and supervisors, met twice a month to discuss program objectives, evaluation of outcomes, and any items that would enhance the research study and community programs. The emphasis of these meetings was generally on programmatic rather than research issues, but they served as a good conduit to ensure that field staff members were informed of and understood research needs, to ensure that field staff members' observations were included in discussion of research issues and that research decisions were not made without staff involvement, and to coordinate field-based research activities (e.g., surveys of schools in study neighborhoods). These meetings engendered a sense of complementarity between research and practice. Field staff members understood and cooperated with research needs because they were able to contribute to research development.

To establish a sense of community ownership in a project and increase its effectiveness, a nontraditional intervention strategy may be necessary. For example, it may not be possible to maintain a pure control group.

In the St. Louis study, neighborhoods were assigned to control and intervention groups. All residents of intervention neighborhoods were eligible for the program; residents of control neighborhoods were not. Nevertheless, some contamination between intervention and control groups occurred. Mass media reached all neighborhoods. Many participants moved from one neighborhood to another. Also, almost all physicians who cared for study subjects also cared for controls, making the increased awareness of asthma and the importance of regular care available for both groups of children. In addition, offices of all physicians were visited at regular intervals for review of charts of study subjects and controls, increasing awareness of asthma among the office staffs.

These contaminations could reduce differences found between residents of study and control neighborhoods. Through quarterly interviews with caregivers, however, researchers were generally able to track cases, identify those who moved from a study to control neighborhood, and adjust analyses accordingly.

To establish a sense of community ownership in a project and increase its effectiveness, a nontraditional intervention strategy may be necessary.

When communities are reluctant to use control groups because no one wants to be left out, staging the intervention so that some groups get the intervention before others is one strategy for getting agreement on the use of control groups. In this case, there is the added benefit of having results for the control groups before and after they receive the intervention. The New York project did this, enabling all 40 clinics in BCH to receive training without compromising the original study design.

When evaluating asthma in minorities and the effectiveness of interventions, it may be helpful to consider the following areas:

Process Measures

- Is the prevalence rate in the treatment site less than the actual or expected community prevalence rate? If so, screening should be conducted to identify new cases.

- Do the families receive continuing, preventive care? Do they make scheduled visits for preventive asthma care as well as sick visits? Do they have the skills and resources needed to carry out the therapeutic plan? Do families perceive the physician as a partner?
- Have physicians prescribed appropriate therapy? Are patients with moderate or frequent symptoms receiving daily anti-inflammatory therapy? Are the patients or families given a written management plan that allows them to make some adjustments on their own according to changing circumstances, such as onset of a cold?
- Have families been educated about asthma? Do they accept the diagnosis, and are they able to carry out the management plan?
- Have members of the community learned that asthma is serious? That those with asthma can lead full and active lives? That when symptoms occur, they should be dealt with? And that when symptoms persist, help should be sought?

Final Outcome

- Is asthma well controlled in children and are they fully active? Are they missing fewer days from school? Are days with limited activity or nights with sleep disturbance infrequent? Are emergency visits and hospitalizations rare? Has the impact of the illness on family life been minimized?

Evaluations of asthma management programs should be multidimensional.

Several characteristics of asthma suggest the use of multiple indicators to evaluate asthma management programs. First, there is no "gold standard" measure of asthma management. Symptoms, lung function, avoidance of unnecessary acute or emergency care, and general quality of life are all pertinent. Second, individual measures may be ambiguous. Frequent symptoms may represent asthma that is difficult to control or failure to follow regimens that would be adequate to control mild asthma. Reports of symptoms are also subject to a number of reporting biases (such as seeking to report socially appropriate patterns or seeking to please the interviewer). Although increases in reports of symptoms may represent increased morbidity, such increases among those who have previously ignored symptoms may reflect increased sensitivity to symptoms as a beneficial result of asthma education.

The significance of ED visits may also be ambiguous. Although they may represent acute symptoms requiring urgent or emergency care, some low-income patients may use the emergency department as a source of primary care because of barriers to regular outpatient care. On the other hand, waiting too long to seek emergency care has also been implicated in asthma deaths. The St. Louis researchers reviewed records of emergency visits to confirm the diagnosis of asthma and to note the treatment used for the asthma. Use of nebulized bronchodilators during the visit and prescription of prednisone at discharge were taken to indicate acute asthma, as opposed to use of the emergency department as a source of regular care or to refill prescriptions or other nonemergent treatment.

All of these factors suggest that a number of measures should be used as outcomes for asthma management research. The use of a number of measures represents, in turn, the multidimensional nature of asthma.

DATA ANALYSIS AND MISSING DATA

Power analyses should take into consideration the likelihood of missing data, particularly when evaluating an intervention with multiple followup time points.

In New Mexico, the rural nature of the State and distances that patients had to travel for followup care caused otherwise compliant patients to miss one or more followup visits in Albuquerque. This situation resulted in the belief that it is a good idea for power to be conservative and therefore to overestimate the sample size needed to detect a desired effect. In addition, data analysis methods should include these cases that are missing information for one or more time points (for example, random effects modelling). "Complete-case only" analyses can misrepresent intervention effect sizes.

Power calculations for the Texas group were based on a potential dropout rate of 25 percent. This is close to the dropout rate observed by other investigators in longitudinal studies of patient interventions.

In the New York project, the researchers estimated 20 percent loss to followup in the year following the program (for family interviews), but the actual rate was 50 percent, which reduced the ability to detect differences between the program and control group parents.

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Practical Insights: Public Health Notes

Public health activities were identified as those attempting to improve the management of asthma in groups of people in communities and schools. This section offers suggestions for planning and implementing asthma interventions from a public health perspective.

Key Lessons Learned

Planning an Intervention

- Interventions can be strengthened through partnerships between public and private organizations.
- A "lead agency" approach can be an effective option for program governance of a community-based intervention.
- Public health planners should understand how patients interact with the medical systems in the targeted area.
- Intended audiences should be involved in the development of educational programs.
- Factors that affect health care providers' willingness to adopt new practices should be recognized and addressed.

Implementing an Intervention

- Interventions should address participants' attitudes, beliefs, behaviors, skills, and knowledge.
- Consideration should be given to cultural factors, reading level, language barriers, format of materials, and convenience to participants.
- A diversity of groups should be targeted through a broad range of activities.
- Simple messages can aid public education efforts.
- A neighborhood asthma camp is a useful strategy for educating urban families.
- Group asthma education is a challenge in rural areas.
- Lay personnel can be used as asthma educators.
- Compensation is an important factor in staff recruitment and retention.

PLANNING PHASE

Viable partnerships can be established between public and private organizations.

Developing partnerships was an important component in three of the asthma intervention projects. In each case, the partnerships brought together resources that are essential in managing and controlling asthma.

In New York, the department of health, which operated more than 40 primary care clinics for young children, formed an alliance with a medical school that had expertise in clinical care and health education to create a model that provided continuing state-of-the-art primary care to children with asthma.

In New Mexico, the State-funded Children's Medical Services (which provides care for children with serious health problems) combined its services with expertise from a university-based medical center to improve clinical care and health education for underserved rural minorities.

In St. Louis, a private, not-for-profit community organization formed an alliance with a university medical center that has clinical services to respond to needs identified in the community. In Washington, D.C., and Baltimore, a partnership with the school systems was created. School systems tend to be very concerned with the health of their children (as well as test scores and absenteeism) and are usually willing to enter into a partnership with a reputable university or research institution providing the schools gain something from this partnership.

A "lead agency" approach to program governance is effective in engaging neighborhood residents to plan and implement asthma education and management programs.

The St. Louis project used a local, experienced settlement house and social service and health agency (Grace Hill Neighborhood Services) to organize the planning and direction of its program. Neighborhood Wellness Councils, composed of neighborhood residents and Grace Hill clientele, were organized in several neighborhoods to conduct program planning, recruit neighborhood residents to staff positions within the program, and recruit children and caregivers into the program. The lead agency approach takes advantage of the agency's existing links to the community and program credibility. However, working with a lead agency also may bring with it the agency's limitations. For instance, if the agency has not already established links to important groups, the new program may have trouble reaching those groups.

Interventions should be based on an understanding of the medical systems involved and how children and their families interact with the systems.

In St. Louis, it was found that most families received only episodic, acute care and had received little information about treating asthma as a chronic illness. The program staff needed to help families identify appropriate sources of care in addition to addressing other problems in asthma management.

The New York program addressed the problem of overreliance on crisis care by emphasizing that regular preventive care at BCH could reduce families' need for emergency care. Families were provided with an asthma information card (see appendix III) that could be shown to health care providers (e.g., hospital emergency department staff, clinic staff, or private physicians) if the children needed to be seen when the child health clinics were closed. The card includes information about the child's medications and the name of the primary care physician and indicates that the child was enrolled in a program for preventive asthma care under the guidelines established by the NHLBI.

Intended audiences should be involved in the development of educational programs.

Focus groups consisting of children with asthma and their parents were used in the Texas intervention to obtain feedback on educational videotapes as they were developed. Flip-chart materials also were pilot-tested with families. The focus groups and pilot-testing identified several minor problems, including specific words that were not easily understood and additional content areas that families felt were important.

In St. Louis, a number of standard asthma education programs were adopted and implemented through a community organization approach that involved tailoring and revision of programs by the intended audience. Although some control over program content was necessarily lost as a result of this tailoring, the researchers felt that the time and resources necessary to revalidate the program curricula in each new modification would probably reduce the enthusiasm of the community for the program.

The Washington, D.C./Baltimore researchers developed and named a six-session curriculum for children based on their input. The program was called the A+ Asthma Club because elementary school children prefer the idea of a club rather than a class. Creating a club atmosphere for children in small groups gave each child time to talk and participate.

IMPLEMENTATION PHASE

Educational Content and Format

Interventions should address attitudes, beliefs, behaviors, and skills of the intended group, not just knowledge. In developing materials, consideration should be given to ethnic and cultural appropriateness, reading level, and language barriers.

The St. Louis group has followed a series of steps to promote quality control in adapting established educational curricula to the low-income, African American neighborhood setting. (1) No curricula are considered for adoption unless they have been validated in other studies. (2) Prior to developing education materials, audience input is secured, either through ongoing consideration of program progress and emerging needs among wellness councils and staff or through explicit focus groups of children, caregivers, and other neighborhood residents. (3) Focus group findings or staff and volunteer discussions are then reviewed by staff and wellness councils. This leads to a decision to proceed with curricula development and identification of available materials. (4) Agency and university staff and wellness council members then work to develop the curriculum piece, following established educational procedures of identification of key curricula concepts, attention to reading level and ease of comprehension (limited number of themes, simple vocabulary, short sentence length, commonly understood symbols, emphasis on illustrations, easy to comprehend headings and format, short line width, adequate type size [Doak et al., 1985; Kirsch and Jungblut, 1986; Kozol, 1985; Redman, 1984]), and consideration of audience knowledge and attitudes. (5) If the curriculum piece is planned for continued or widespread use, pilot tests are conducted with the intended audience in the setting in which they will be used. Even if not explicitly pilot-tested, materials are re-reviewed by wellness councils and other staff and volunteers before final production.

Intended audiences should be involved in the development of educational programs.

The Washington, D.C./Baltimore researchers emphasized that written material should be supplemented with personal instruction or audiovisual aids. New material should be related to old. Selecting readable print size, using bold

face type, and using pictures are important. Concepts should be illustrated.

In the Texas project, a bilingual Hispanic nurse educator worked one-on-one with a child with asthma and his or her parents, conducting each educational module in either Spanish or English depending on parent and child preferences. The one-on-one format was employed to increase discussion and to allow the nurse educator to individualize the module to each family's circumstances. Educational materials were printed in Spanish and English at a fourth grade comprehension level. Each lesson was reinforced by colorfully illustrated flip cards in English and Spanish that visually depicted essential points. Children and adults portrayed on the flip cards were Hispanic in appearance to enhance identification value. At the conclusion of each module, families received a take-home pamphlet in English and Spanish outlining key messages. Each point of information on the pamphlet was reinforced with an illustration to reduce reliance on reading comprehension.

Peer modeling in the Texas project was provided by eight videotapes featuring four Hispanic children with severe asthma (two boys and two girls), ages 6 to 12. These children were shown managing their asthma at home, at play, and at school; discussing in their own words why these behaviors have been helpful; and sharing their feelings about asthma's impact on their life and schoolwork. The role model videotapes were produced in a documentary format to enhance realism. The conventional technique of staging scripted scenes using actors to portray children and parents often produces stilted dialogue and contrived situations that are unappealing to children accustomed to sophisticated video production techniques. The on-camera narrator for the videotapes was a bilingual Hispanic female the same age as most of the mothers in the educational program. The videotapes featured the narrator speaking in Spanish and

Language barriers and cultural appropriateness should be considered in curricula development.

presented interviews with Spanish-speaking parents or, occasionally, an English-speaking parent with a Spanish translation dubbed-over by the narrator. The language in the English videotapes was handled in a similar manner. All four role model children spoke in English on the videotapes since all children in the Texas project preferred English for peer conversation. Interactions between children and parents on the videotapes were presented in Spanish or English depending on the families' language preferences.

New Mexico selected the Open Airways curriculum since it was developed for Hispanic patients. It was condensed into four sessions and updated to include peak flow monitoring and new medications. The researchers found that families and health care providers preferred having one booklet that accurately covered important asthma information, as opposed to using a variety of materials. Step-by-step asthma action plans for dealing with increased symptoms and low peak flow also were extremely helpful to both families and providers.

The New York intervention with BCH clinic staff used interactive teaching methods that explicitly sought to identify the beliefs, behaviors, and organizational concerns of the clinic teams and involved them in activities to resolve them. For example, using a strategy developed by Kurt

Lewin called "force field analysis," clinic teams were asked to develop a strategy for dealing with a perceived problem and to begin implementing it the next day in their clinic. A discussion of the theories of health behavior with the clinic teams was very helpful to the staff in addressing family understanding of asthma and how to work with these families to control asthma.

Simple messages about asthma can aid public education efforts.

The St. Louis public education program was based on three basic messages to encourage and assist children with asthma and their parents to receive appropriate asthma care: Take asthma seriously; take asthma medicine for asthma symptoms; and when symptoms persist or worsen, get help. These messages were based on studies of asthma deaths that implicated misunderstanding of basic aspects of asthma care and neglect of asthma medicines. Thus, relatively simple messages can make a big difference. Simple messages are easily understood, and nonprofessional staff members without extensive training can promote them effectively. They can also be covered in simple promotions that do not require extensive time or attention from audiences.

Information about local resources should be incorporated into community education programs.

Through the course of various educational activities in the St. Louis program, it became apparent that caregivers were frustrated over how to tap community resources to get the care they needed for their children's asthma. They were impatient with general asthma education that did not address these specific problems. This resulted in emphasis on exchange of information among participants and question-and-answer sessions, often using an "Ask the Doc" format.

Educational interventions to improve asthma care in children should target the children and their families, health care providers, teachers, day care providers, peer groups, and other community members. In this way, patients can receive consistent messages from all with whom they come into contact.

Modalities of Implementation

Asthma education that is incorporated into a range of activities is more attractive than formal classes.

The St. Louis researchers found very little interest on the part of parents and their children in asthma education classes and similar formal programs for asthma education. Consequently, greater emphasis was placed on integrating asthma-related messages into other educational programs (e.g., general wellness courses taught through a neighborhood college maintained by Grace Hill), neighborhood activities, and mass media. Samples of educational activities include "Asthma Skate-Outs" sponsored by local merchants, asthma awareness prayer programs in neighborhood churches, in-service training for neighborhood school staff, health fairs, proclamation of March as Asthma Month by the mayor of St. Louis, and media coverage through newspapers and electronic media, including call-in radio shows with Neighborhood Asthma Coalition representatives answering callers' questions.

Information about local resources should be incorporated into community education programs.

The concept of the "teachable moment" was used by the St. Louis project to integrate asthma education into a range of attractive activities. This approach is borrowed from classroom

teaching strategies based on Robert Gagné's book *The Conditions of Learning* (Gagné, 1977). The teachable moment approach pulls individual concepts from standard curricula to stand alone during the course of asthma-related activities. It requires that adults who teach and supervise students have a repertoire of asthma information and a good sense of how individual facts can be integrated into the context of an activity at hand. With the teachable moment approach, issues that arise during the course of a variety of program activities can be used as a platform for asthma management lessons.

In scheduling educational interventions, convenience is a significant factor for patients and their families.

In scheduling educational interventions, convenience is a significant factor for patients and their families.

The Texas researchers originally tried to schedule all of the patient education sessions immediately before or after a scheduled physician visit. However, some families preferred to come at another time. Teaching sessions also had to be scheduled around school and work schedules. In New Mexico, because of long distances to travel, families preferred having classes linked to a clinic visit. Stand-alone classes would not have worked.

Some of New York's clinics had clinical sessions where a majority of the scheduled patients had asthma; this made holding group asthma education sessions convenient for families and staff. (See clinical notes section, page 15.) A variety of modalities (e.g., telephone calls, camps, group education classes, home visits) may be useful for followup and reinforcing asthma education.

In St. Louis, providing transportation to program activities greatly increased attendance. This may be important in settings where participants do not have their own means of transportation, where public transportation is not adequate, and in high crime areas.

A toll-free telephone number is a valuable resource for asthma education in rural areas.

A toll-free telephone number set up for easy information access by the New Mexico project was well used not only by families but also by other health care providers, pharmacists, and case managers.

A neighborhood asthma summer camp can be a useful approach to addressing not only asthma but also the social and health needs of an urban community.

The St. Louis researchers found a neighborhood asthma summer camp to be a valuable means of getting the community involved in asthma education activities. Holding the camp within urban neighborhoods, rather than in rural areas, allows asthma education to reach friends and family members who otherwise could not participate. The camp curriculum includes interactive discussions and games to increase asthma knowledge; development of problem-solving and communication skills; crafts such as T-shirt painting and full-body drawings, aimed at enhancing self-esteem; physical activities such as kickball, exercises, breathing techniques, singing, and dancing, aimed at giving children with asthma confidence in their physical capabilities; visits by a professional storyteller with stories about African American heroes who overcame hardships; and field trips to educational attractions in the St. Louis area. Older campers serve as counselors to younger campers, which gives the counselors an opportunity to learn while they teach. The camp is held from midmorning until midafternoon for 1 week in each of several neighborhood sites. Transportation is provided and has been judged essential to the camp's success.

In rural areas, many factors can affect the ability of families to attend group asthma education classes and present additional problems for the project staff.

Families in the New Mexico project had to travel to Albuquerque to attend group educational sessions. During the same day, children received clinical evaluation, but this often involved a very long wait. Finding space for the classes, arranging babysitting for young children during the classes, and bad weather contributed to the researchers' logistical problems. Families who missed one of the sequentially designed classes had to be rescheduled, which created further difficulties.

Home visits are not always necessary to reinforce asthma education.

The New Mexico investigators found that in some cases one or two visits by the home family educator, rather than six, would have been sufficient. In other cases, families may benefit from a different type of intervention (e.g., peer counseling for teenagers).

There was extensive use of telephone calls and of meetings at neighborhood events in St. Louis.

Lay personnel can be valuable to community asthma education programs.

Originally, there was concern that telephone calls and meeting at neighborhood activities would be insufficiently intense, relative to home visits. However, both neighborhood staff members and program participants indicated many concerns about home visits in light of general concern about neighborhood crime. Also, the telephone calls and meetings at community events appear to have supported effective and helpful relationships between staff and participants. Home visits are now conducted occasionally but not on a regular basis.

Recruiting, Training, and Retaining Staff and Volunteers

Lay personnel can be involved in the development and implementation of asthma education programs.

Family educators (parents of children with asthma) in the New Mexico program were identified by health professionals in the Pediatric Pulmonary Division and then interviewed by telephone to determine interest and qualifications (see appendix III). The educators were trained to reinforce asthma education and provide support to families. Some went on to contribute their skills to the community at large by being involved in asthma camp and teaching the Open Airways for Schools curriculum. Several went to school for nursing and respiratory therapy.

In St. Louis, neighborhood residents were recruited to provide individualized basic asthma education, assistance, and social support to children with asthma and their caregivers. The program's focus on simple messages increased the likelihood of successfully training nonprofessionals to conduct asthma education. The workers also provided general assistance in program development and implementation.

Creating a detailed and easy-to-follow curriculum with scripted sections for people to use as models allowed people with no background in asthma to

learn quickly and present the Washington, D.C./ Baltimore program without assistance.

Selecting people who had asthma themselves or who had a family member with asthma did not always prove to be advantageous. Although these individuals were generally familiar with asthma and eager to help children with asthma, special attention had to be given to be certain the program messages were delivered without bias when these messages contradicted educators' personal beliefs about asthma management (e.g., believing it was acceptable to have pets or believing in homeopathic or "alternative" treatments for asthma).

Compensation is an important factor in recruitment and retention of staff.

Compensation is an important factor in recruitment and retention of staff.

Initial plans to recruit volunteers for the St. Louis program proved unworkable. The researchers found that payment is necessary and appropriate when regular execution of extensive responsibilities is desired. Thus, neighborhood residents have been recruited as paid staff. Moreover, increasing the salary for their positions reduced an unacceptable turnover rate.

Part-time salaries may not be sufficient to retain staff. Several health educators left the New Mexico and Washington, D.C./Baltimore studies because the work was not full time.

Strategies to maintain feelings of unity with the community are useful in retaining neighborhood residents as project staff.

The St. Louis program was plagued initially by a high level of turnover among staff members recruited from neighborhood residents. Factors such as unclean home environments, gang incidents, and illiteracy created anxieties among the peer neighborhood workers as to their role in the neighborhood. To maintain homogeneity among the workers and intended residents, the researchers revised training to include attention to the role of the workers and reduced emphasis on home visits. These changes helped increase community staff retention, job performance, and impact by enabling them to be more accepting and work with a greater sense of unity with those they seek to help.

Regular (if possible, biweekly) meetings with project staff are important for troubleshooting and maintaining staff skills, interest, and cohesiveness.

Barriers to Implementation of Intervention

Social and economic barriers can inhibit implementation of an intervention.

In New Mexico, money for medications, medical care, and travel expenses posed a huge barrier. Inability to maintain a vehicle for traveling long distances was mentioned frequently as a barrier. The New Mexico researchers also found that some patients were hesitant to admit if they did not understand instructions. This lack of communication posed another barrier to care.

Lack of pharmacies, especially 24-hour pharmacies, in the St. Louis program neighborhoods posed another barrier to care. Participants' hesitation to use medications daily for fear of dependence and increased tolerance also inhibited asthma management.

Interventions for health professionals require tremendous time and effort.

(See clinical notes section for a full discussion of education for health professionals.)

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Appendix I: Additional Minority Asthma Intervention Projects

National Heart, Lung, and Blood Institute

The National Heart, Lung, and Blood Institute is currently funding three projects, each for 3 years, under the title "Developing and Implementing at the State and Local Level Educational Strategies and Interventions for Controlling Asthma in Inner-City and High-Risk Populations." These programs are briefly described below.

Abt Associates, Inc., and the Dimock Community Health Center
Roxbury, Massachusetts

The goal of this project is to develop a long-term, sustainable, communitywide coalition to reduce asthma morbidity and mortality in the Boston inner-city communities of Roxbury and Dorchester. Abt Associates is developing and evaluating the educational intervention in collaboration with Dimock Community Health Center, an experienced, community-based health and human services agency. A number of other health, administrative, social service, educational, and media organizations in the community are participating in the effort by identifying resources, planning and conducting aspects of the program, and publicizing the campaign in the community and within the participating organizations. This diversity of perspectives has produced a broad range of coordinated educational activities targeted to adults and children with asthma, their families, preschool teachers and family outreach workers, and health care providers. Educational strategies were developed and tested during the first year of the project and are being implemented during the second. During the third year, intervention, evaluation, and documentation will be continued. Additional information about this project is available from David B. Connell, Ph.D., project director, or from Sheila Moroney. Dr. Connell's address is Abt Associates, Inc., 55 Wheeler Street, Cambridge, MA 02138; the telephone number is (617) 492-7100. Ms. Moroney's address is Dimock Community Health Center, 55 Dimock Street, Roxbury, MA 02119; the telephone number is (617) 442-8800.

Fresno Asthma Project
Fresno, California

The Fresno Asthma Project is a collaborative effort among the San Joaquin Valley Health Consortium (a consortium of 26 community health services agencies and health professions education institutions), Kaiser Permanente Medical Care Program (a health maintenance organization), the American Lung Association of Central California, and the American Institutes for Research (a behavioral and social science research institute) to control asthma in the county of Fresno, which has one of the highest asthma mortality rates in the United States. The intervention involves a patient/family education component and a professional education component, each supplemented by a multimedia campaign to raise public awareness about asthma

and increase understanding about the disease and its treatment. Existing asthma education programs for patients are being adapted for the ethnically diverse community in Fresno and used for asthma education in a variety of settings. Professional education is being conducted through annual asthma conferences, periodic grand rounds at key medical centers, and inservice programs for school personnel. Additional information about this project is available from Sandra R. Wilson, Ph.D., principal investigator. She can be reached at the American Institutes for Research, P.O. Box 1113, 1791 Arastradero Road, Palo Alto, CA 94302; the telephone number is (415) 493-3550.

Macro International, Inc., and Baylor College of Medicine
Houston, Texas

Baylor College of Medicine is working with Macro International, a computer technology applications company, to develop and implement an asthma education program for 7- to 12-year-old African American and Hispanic children in the inner-city areas of Houston. The project is using interactive multimedia and decision-support-systems technology to tailor instruction to individual children with asthma and generate specific recommendations for each child's family, health care provider, and school. Currently, the computer-based instructional system is being tested with children during scheduled visits to health care providers. The tailored instruction is based on data on the child's medical history and personal characteristics (such as age, gender, race or ethnicity, culture, and literacy). Eventually, the system will be applied to other settings, such as emergency departments, where it will encourage regular primary care and create individualized asthma management plans. Additional information about this project is available from Robert S. Gold, Ph.D., Dr.P.H., principal investigator. Dr. Gold can be reached at Macro International, Inc., 11785 Beltsville Drive, Calverton, MD 20705; the telephone number is (301) 572-0200.

National Institute of Allergy and Infectious Diseases/National Institute of Environmental Health Sciences

National Cooperative Inner-City Asthma Study

Since 1991, the National Cooperative Inner-City Asthma Study has been involved in the design, implementation, and evaluation of a comprehensive intervention program to reduce asthma morbidity among urban African American and Latino children. Eight centers are participating in this study, which has been conducted in two phases. In phase I, baseline data on health care utilization and access, adherence to medications, family functioning, home environment, and household demographics were collected and evaluated. Physiological data were also collected and analyzed. Phase II consists of a multidimensional approach to reduce asthma morbidity by training families to translate asthma knowledge into health-promoting skills and behavioral changes. A key component of the intervention is the use of asthma counselors, specially trained social workers who work closely with families over an extended period of time, troubleshoot, and empower families to address a variety of problems. A standardized risk assessment tool was created to screen individual children for the medical, psychosocial, and environmental risk factors identified in phase I so that the intervention could be appropriately tailored. For additional information about the National Cooperative Inner-City Asthma Study, please contact the Office of Epidemiology and Clinical Trials, National Institute of Allergy and Infectious Diseases, Solar Building, Room 4A23, 6003 Executive Boulevard, Rockville, MD 20852; the telephone number is (301) 496-0982.

Appendix II: Resources

Publications

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Materials

Educational materials and research tools from several of the projects are available for sale from the National Technical Information Service (NTIS). Cost and ordering information can be obtained by calling (703) 487-4650 or writing to NTIS, 5825 Port Royal Road, Springfield, VA 22161.

An Intervention for Hispanic Children with Asthma (Texas project)

- Flipcharts (text in both English and Spanish)
  - Symptoms (7 cards)
  - Peak Flow (3 cards)
  - Medications (4 cards)
  - Causes (6 cards)
- Videotape (available in English and Spanish); each tape contains the following segments:

  "Recognizing asthma symptoms—Before it's too late" (4:31)

  "Avoiding trips to the emergency room" (3:54)

  "I can do it: exercise and asthma" (3:58)

  "Your breathing meter: it can make a difference" (3:52)

  "Asthma medicines: they will help you" (3:54)

  "Breathe easy: follow your medication plan" (3:47)

  "The fight against asthma: causes of asthma" (4:42)

  "Cigarette smoking and asthma: a bad combination" (3:47)
- Handouts/Worksheets (text in both English and Spanish)
  - Symptoms: "What is easy to do?"
  - Peak flow: "How to use your peak flow meter" and "Daily record chart"
  - Medications: "Medicines"
  - Causes: "Asthma causes"
- Instructional guide (includes behavioral and learning objectives, a list of required equipment/supplies, and a teaching outline for each of four teaching modules)
- Enrollment questionnaires (parent version available in English and Spanish; child version in English only)

A Self-Management Educational Program for Hispanic Asthmatic Children (New Mexico project)

- *Your Child and Asthma* (comprehensive lay-language booklet describing asthma causes, symptoms, and treatment; 30 pages)

Neighborhood Asthma Coalition (St. Louis project)

- *Neighborhood Asthma Coalition Summer Day Camp 1995: Curriculum Guide for Program Coordinators* (contains teaching instructions, script, and health messages for daily asthma lessons)
- *Neighborhood Asthma Coalition: Physician's Guide* (includes patient education materials for outpatient settings)

Community Interventions for Minority Children With Asthma (Washington, D.C./ Baltimore project)

- *The A+ Asthma Club* (illustrated workbook for six meetings)
- *The A+ Asthma Club: A Book for the Family*
- Parental Baseline Questionnaire

Other Asthma Information Sources

The following organizations are active in asthma education and research. For information and materials, contact:

- Allergy and Asthma Network/Mothers of Asthmatics, Inc. (1-800-878-4403)
- American Academy of Allergy and Immunology (1-800-822-2762)
- American College of Allergy and Immunology (1-800-842-7777)
- American Lung Association (local chapters listed in telephone directories)
- Asthma and Allergy Foundation of America (1-800-727-8462)
- National Jewish Center for Immunology and Respiratory Medicine Information Service (1-800-222-5864)
- National Institute of Allergy and Infectious Diseases (301-496-5717)
- NHLBI Information Center (301-251-1222)

Appendix III:
Instruments

ASTHMA TREATMENT PLAN FORM (NEW YORK PROJECT)

New York City Department of Health
Bureau of Child Health (L6)

Clinic Stamp

ASTHMA TREATMENT PLAN FOR _____
First Name *Last Name*

Medication	At the FIRST sign of a cold	When cough or wheeze is present	As soon as cough and wheeze have stopped.	After there is no cough or wheeze for 2 weeks, even when running.		
Times per day						

Do not delay. Start the medicines immediately.

If the medicines make your child uncomfortable (headache, upset stomach, irritability), telephone us at the clinic. If you can't reach us right away, cut the dose in half until you can telephone.

If child needs a refill of medicine, call us or come to the clinic.

Go to the hospital **immediately** if:

1) your child has severe trouble breathing, for example:

a) the skin of your child's neck, ribs or stomach sucks in with each breath
b) your child can't walk or talk because of breathlessness

2) your child develops blue fingernails or lips.

_____
Doctor's Name

_____
Nurse's Name

_____
Date Telephone

Please read the IMPORTANT THINGS TO REMEMBER, on the back of this form.

CH 180 (3/94)

IMPORTANT THINGS TO REMEMBER

Discussed by:

MD RN

❑ ❑ Our goals for your child are that he or she will be able to:

- sleep through the night
- run without cough or wheeze
- have a cold without severe symptoms of asthma.

❑ ❑ Keep your scheduled appointment for asthma because:

- preventive care can make attacks less frequent or severe
- we need several visits to adjust the type and dose of medications that are best for your child.

❑ ❑ Prevention is even better than treatment. If you find there is anything that makes your child's asthma worse, discuss it with your doctor.

❑ ❑ Smoke makes asthma worse. Because you love your child, keep the air smoke-free.

Please call us between _____ *am* and _____ *pm* if you have any questions or problems.

CH 180 (3/94)

Asthma Self-Monitoring Plan (New Mexico Project)

ASTHMA SELF-MONITORING PLAN

PEDIATRIC PULMONARY DIVISION
University of New Mexico
Department of Pediatrics

Name _____ Date _____

▶ *Below are guidelines to help you in managing your child's asthma. The different zones are based on a traffic light example.*

Green Zone _____ to _____ (80 - 100% of best)

This is the range you want the peak flows to be in. It means the asthma is under good control. Continue to give routine medicines.

Yellow Zone _____ to _____ (50 - 80% of best)

In this range peak flows are starting to fall. Lung function is beginning to fall even though there may be no noticeable symptoms yet.

YOU SHOULD GIVE YOUR CHILD A NEBULIZER TREATMENT AND IMMEDIATELY AFTERWARDS CHECK THE PEAK FLOW.

→ IF WORSE (RED ZONE), CALL YOUR DOCTOR OR TAKE TO THE EMERGENCY ROOM IMMEDIATELY

IF THE PEAK FLOW IS IN THE GREEN ZONE.

↓

NO FURTHER TREATMENT IS NECESSARY CONTINUE TO GIVE ROUTINE MEDICINES..

IF THE PEAK FLOW IS STILL IN THE YELLOW ZONE REPEAT ANOTHER NEBULIZER TREATMENT.

↓

IF PEAK FLOW CONTINUES STAY IN THE YELLOW ZONE YOU MAY REPEAT THE TREATMENT AGAIN.

↓

IF PEAK FLOW IS AGAIN IN THE YELLOW ZONE GIVE A 4TH TREATMENT.

↓

IF STILL IN THE YELLOW ZONE AFTER 4 TREATMENTS, CALL THE DOCTOR OR TAKE TO THE EMERGENCY ROOM IMMEDIATELY

If you notice improvement after a treatment, but your child needs a treatment every 2 hours for over 4 hours, you need to call the doctor also.

Red Zone: Below _____ (below 50% of best)

This is the **danger zone** and time to get immediate help. Give a nebulizer treatment and contact the doctor while giving the treatment. May repeat another treatment while waiting for the doctor to call back. If unable to reach the doctor, take to the Emergency Room immediately.

NOTE: If your child does not take nebulizer treatments and only uses inhalers he/she can take extra puffs for relief. The maximum is 4 puffs of Ventolin or Proventil every 15 minutes for one hour. If your child is not significantly better after this, call the doctor.

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Asthma Management Plan—When Symptoms Increase (New Mexico Project)

NAME _____ DATE _____

ASTHMA MANAGEMENT PLAN — WHEN SYMPTOMS INCREASE

If your child gets a cold, has increased wheezing or coughing, you can give an extra nebulizer treatment.

If **WORSE** call your doctor, or take to the **Emergency Room immediately**

If **BETTER**, continue regular daily medicines and observe

If needing treatments every 2 hours for over 4 hours, **call the doctor**

The maximum is 4 treatments in an hour –1 treatment every 15 minutes. **Before giving extra treatments**, check to make sure your child's heart rate is not above _____ beats per minute. To check the heart rate count the number of beats for 15 seconds and multiply by 4.

Your doctor may want you to have Pediapred at home in case of severe episodes when increasing treatments is not enough. **Call your doctor first** to find out if you should start the Pediapred.

If **NOT** better, or if only slightly improved, give another treatment

If **not better**, or if only slightly improved, can give another treatment

If **not better**, or if only slightly improved, can give a 4th treatment

If not better CALL DOCTOR, or take to the **Emergency Room immediately**

INSTRUCTIONS FOR PEDIAPRED

Take _____ (_____mg) every _____ hours for _____ days, then decrease to _____ every _____ hours for _____ days, then **STOP** the medicine. If your child is **not better, call the doctor**.

Theresa Anaya, MD	Bennie McWilliams, MD	Shawn Feather, RN	Call **1-800-439-3916** during the day Monday through Friday. Evenings and weekends call UNM Hospital **1-843-2111** and ask for the **Pediatric Pulmonary Doctor** on call.
Loretta Cordova, MD	Sandra Murdock, MD	Jean Hanson, RN, MN	
Roni Grad, MD	Shirley Murphy, MD	Mary Russell, RN	
Ann Halbower, MD	Evelyn Oden, MD	Pam Schueler, RN, MSN	

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Asthma 1...2...3 Plan (St. Louis Project)

Respiratory Care & Nursing Service Departments
Emergency Unit

Asthma 1...2...3 Plan

for

Name: _____

Phone #: _____ (Zip Code): _____

Patient Stamp

1. TAKE YOUR MEDICINE		
Name:	Name:	Name:
Amount:	Amount:	Amount:
Times:	Times:	Times:

2. KNOW YOUR SYMPTOMS

Early Warning Signs

The following should make you stop what you are doing:

- Tightness of the chest
- Shortness of breath
- Wheezing
- Coughing
- Peak flow below 80% of personal best (below _____)

You should continue to take your medicines: _____, _____ and call your doctor.

Late Warning Signs

Sometimes attacks get worse and do not respond to treatment. If you have:

- Trouble talking
- Use of neck/stomach muscles
- Need medicine more than every _____ hours
- Peak flow below 50% of personal best (below _____)

You should take an extra dose of _____ and call your doctor immediately!

If you cannot contact your doctor, go to the Emergency Unit for further treatment!

3. FOLLOW-UP APPOINTMENT

It is important for you to be seen by your doctor **within 3 days**:

Doctor: _____ Phone #: _____

At this appointment your doctor can:

- Make sure that your medicine is working
- Talk about future treatment plans
- Answer your questions

Additional Notes/Comments:

Date:	Time:	
Parent:	Therapist:	Nurse:

St. Louis Children's Hospital
One Children's Place
St. Louis, Missouri 63110-1077
314-454-6000

DIAGNOSE AND CLASSIFY SEVERITY OF ASTHMA

Establish Diagnosis

Ask patient or parents: Does the patient have

- Recurrent attacks of wheezing?
- Troublesome cough or wheeze at night or early in the morning?
- Cough or wheeze after exercise?
- Cough, wheeze, or chest tightness after exposure to airborne allergens or pollutants?
- Colds that "go to the chest" or take more than 10 days to clear up?
- Antiasthma medicine? How frequently does the patient take it?

Measure lung function with spirometry or peak flow meter, if available.

Classify Severity Of Asthma

	Clinical Features Before Treatment	Daily Medication Required To Maintain Control
STEP 4 Severe Persistent	Continuous symptoms Frequent exacerbations Frequent nighttime asthma symptoms Physical activities limited by asthma symptoms PEF or FEV, • ≥60 % predicted; • variability >30%.	Multiple daily controller medications: high doses inhaled corticosteroid, long-acting bronchodilator, and oral corticosteroid long term.
STEP 3 Moderate Persistent	Symptoms daily Exacerbations affect activity and sleep Nighttime asthma symptoms >1 time a week Daily use of inhaled short-acting β_2-agonist PEF or FEV, • >60% – <80% predicted; • variability >30%.	Daily controller medications: inhaled corticosteroid and long-acting bronchodilator (especially for nighttime symptoms)
STEP 2 Mild Persistent	Symptoms >1 time a week but <1 time per day Exacerbations may affect activity and sleep Nighttime asthma symptoms >2 times a month PEF or FEV, • ≥80% predicted; • variability 20–30%.	One daily controller medication: possibly add a long-acting bronchodilator to anti-inflammatory medication (especially for nighttime symptoms).
STEP 1 Intermittent	Intermittent symptoms <1 time a week Brief exacerbations (from a few hours to a few days) Nighttime asthma symptoms <2 times a month Asymptomatic and normal lung function between exacerbations PEF or FEV, • ≥80% predicted; • variability <20%.	• Intermittent reliever medication taken as needed only: inhaled short-acting β_2-agonist • Intensity of treatment depends on severity of exacerbation: oral corticosteroids may be required.

The presence of one of the features of severity is sufficient to place a patient in that category.

Source: National Heart, Lung, and Blood Institute. *Asthma Management and Prevention: A Practical Guide for Public Health Officials and Health Care Professionals.* Bethesda, MD, in press.

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Management of an Asthma Attack: Home Treatment

Assess Severity	**Initial Treatment**
Cough, breathlessness, wheeze, chest tightness, use of accessory muscles, suprasternal retractions, and sleep disturbance. PEF less than 80% of personal best or predicted.	*Inhaled short-acting beta$_2$-agonist up to three treatments in 1 hour.* *(Patients at high risk of asthma-related death should contact physician promptly after initial treatment.)*

Response to Initial Treatment is...

Good *if...*	***Incomplete*** *if...*	***Poor*** *if...*
Symptoms subside after initial beta$_2$-agonist and relief is sustained for 4 hours. *PEF is greater than 80% predicted or personal best.* ***ACTIONS:*** • *May continue beta$_2$-agonist every 3-4 hours for 1-2 days* • *Contact physician for followup instructions.*	*Symptoms decrease but return in less than 3 hours after initial beta$_2$-agonist treatment. PEF is 60-80% predicted or personal best.* ***ACTIONS:*** • *Add corticosteroid tablet or syrup* • *Continue beta$_2$-agonist* • *Consult physician urgently for instructions.*	*Symptoms persist or worsen despite initial beta$_2$-agonist treatment. PEF is less than 60% predicted or personal best.* ***ACTIONS:*** • *Add corticosteroid tablet or syrup* • *Repeat beta$_2$-agonist immediately* • *Immediately transport to hospital emergency department (see figure 14).*

Source: National Heart, Lung, and Blood Institute. *Asthma Management and Prevention: A Practical Guide for Public Health Officials and Health Care Professionals*. Bethesda, MD, in press.

MEDICAL HISTORY
CMS ASTHMA PROGRAM

DATE _____ UNMH# _____

NAME _____ AGE _____

REFERRING M.D. _____

HISTORY OF ASTHMA

1. Age of onset of symptoms. _____
2. Type of symptoms at onset. _____
3. Type of current symptoms/problems. _____
   a: Nocturnal symptoms _____
   b: exercise symptoms _____
4. Approximate date of last asthma episode. _____
   Describe _____

CURRENT MEDICATIONS:

1. NAME: _____ DOSAGE _____
   FREQUENCY: _____
   METHOD OF DELIVERY: _____ORAL _____INHALED(MDI) _____NEBULIZED
   SIDE EFFECTS: Headaches, nausea, vomiting, sleeplessness hyperreactivity, tremor, school problems (Circle)
2. NAME: _____ DOSAGE _____
   FREQUENCY: _____
   METHOD OF DELIVERY: _____ORAL _____INHALED(MDI) _____NEBULIZED
   SIDE EFFECTS: Headaches, nausea, vomiting, sleeplessness hyperreactivity, tremor, school problems (Circle)
3. NAME: _____ DOSAGE _____
   FREQUENCY: _____
   METHOD OF DELIVERY: _____ORAL _____INHALED(MDI) _____NEBULIZED
   SIDE EFFECTS: Headaches, nausea, vomiting, sleeplessness hyperreactivity, tremor, school problems (Circle)
4. NAME: _____ DOSAGE _____
   FREQUENCY: _____
   METHOD OF DELIVERY: _____ORAL _____INHALED(MDI) _____NEBULIZED
   SIDE EFFECTS: Headaches, nausea, vomiting, sleeplessness hyperreactivity, tremor, school problems (Circle)
5. NAME: _____ DOSAGE _____
   FREQUENCY: _____
   METHOD OF DELIVERY: _____ORAL _____INHALED(MDI) _____NEBULIZED
   SIDE EFFECTS: Headaches, nausea, vomiting, sleeplessness hyperreactivity, tremor, school problems (Circle)

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Medical History Form (New Mexico Project) continued

6. NAME: _____ DOSAGE _____

FREQUENCY: _____

METHOD OF DELIVERY: _____ORAL _____INHALED(MDI) _____NEBULIZED

SIDE EFFECTS: Headaches, nausea, vomiting, sleeplessness hyperreactivity, tremor, school problems (Circle)

OTHER PAST MEDICATIONS:

_____

_____

_____

_____

MEDICAL HISTORY

Hospitalizations _____YES _____NO NUMBER _____

ER visits _____YES _____NO NUMBER IN LAST YEAR _____

Number missed school days for asthma in last year _____

Sinus Infections _____YES _____NO DATE: _____ RX_____

Otitis _____YES _____NO DATES _____ RX_____

Oral prednisone _____YES _____NO Number of Burst in last year _____

Allergy skin testing _____YES _____NO RESULTS _____

Allergy Shots _____YES _____NO

Immunizations up to date _____YES _____NO

TB Test _____YES _____NO DATE_____

Other Medical Problems _____YES _____NO TYPE _____

_____

Had Chicken Pox _____ YES _____ NO

TRIGGERS

URI	_____YES	_____NO	CIGARETTE SMOKE	_____YES	_____NO
EXERCISE	_____YES	_____NO	DUST HOUSE	_____YES	_____NO
ANIMALS	_____YES	_____NO	FOOD	_____YES	_____NO
POLLENS	_____YES	_____NO	COLD AIR	_____YES	_____NO
WEATHER CHANGES	_____YES	_____NO			

NON-SPECIFIC IRRITANTS (perfumes, cleaning agents, etc) _____YES _____NO

SEASONS SYMPTOMS WORSE: SPRING _____ SUMMER _____

WINTER _____ FALL _____

ENVIRONMENT

Cigarette smoking in home? _____YES _____NO WHO? _____

Pets _____YES _____NO TYPE _____

Humidifier _____YES _____NO

Wood Burning Stove _____YES _____NO

Live: _____FARM, _____RURAL, _____SMALL COMMUNITY

FAMILY HISTORY

Number of siblings and ages: _____

_____

_____

Family members with asthma _____

_____

_____

PHYSICAL EXAM

EARS _____ clear
_____ slightly congested (dull TM)
_____ acute otitis

NOSE _____ clear
_____ slightly congested
_____ severe congestion/rhinitis

LUNGS _____ clear
_____ slight expiratory wheezing
_____ loud expiratory wheezing
_____ inspiratory and expiratory wheezing
_____ acute respiratory distress

OTHER _____

Other significant history:

Problems most concerning to family

Problems most concerning to child:

OVER

Medical Plan:

Signature

Date letter dictated

mg46

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ASTHMA SCREENING QUESTIONNAIRE (NEW YORK PROJECT)

Child Health Clinics of New York City
Health and Hospitals Corporation

INITIAL SCREENING TO BE GIVEN AT C/THP VISIT AT AGES 6 MONTHS, 1, 3, and 5 YEARS, AND THEN REPEATED AT EACH C/THP VISIT THEREAFTER

PATIENT STAMP

ASTHMA SCREENING QUESTIONNAIRE

Dear Parent/Caretaker:
The medical team of this clinic will take care of children with asthma on an on-going basis. To find out if any of your children or children you take care of have asthma, please answer the questions below by checking or filling in the correct answer.

1. Please write the name, birthdate, and telephone number of the child being seen by the doctor today.
Also write the name of the child's mother.

_____ Birthdate ___/___/___
Child's First Name Last Name Month Day Year

_____ Telephone # _____
Mother's First Name Last Name

2. Does this child ever have:

Wheezing?	YES ❑	NO ❑	Trouble Breathing?	YES ❑	NO ❑
Frequent Cough?	YES ❑	NO ❑	Tightness in Chest?	YES ❑	NO ❑
Shortness of Breath?	YES ❑	NO ❑			

3. Has a doctor ever told you that this child had:

Asthma?	YES ❑	NO ❑	Bronchitis?	YES ❑	NO ❑
Bronchiolitis?	YES ❑	NO ❑	Asthmatic Bronchitis?	YES ❑	NO ❑

If you answered yes to any of the questions above:

4. Has this child ever been treated by a doctor for this problem? YES ❑ NO ❑
Where is he/she usually treated for this problem? _____

5. Is this a hospital emergency room? YES ❑ NO ❑
A clinic? YES ❑ NO ❑
A private doctor? YES ❑ NO ❑

6. When was your child last treated for this problem? ___/___/___ Month Day Year

7. Do any other children in your home ever have asthma or breathing problems? YES ❑ NO ❑

TO BE COMPLETED BY PHYSICIAN

Please make sure that all questions are answered.
Make appointments for all children that the mother wants treated for asthma.

Impression: ❑ No asthma ❑ Asthma ❑ Undetermined
Disposition: ❑ Follow-up appointment to be scheduled in _____ weeks
❑ Child will be cared for elsewhere at _____

Family screened by Dr: _____ Date ___/___/___ Month Day Year

TO BE COMPLETED AT APPOINTMENT DESK

Date of follow-up appointment: ___/___/___ Month Day Year Registration Number: _____

CH 146 (REV. 5/95) MEDICAL RECORDS

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ASTHMA INFORMATION CARD (NEW YORK PROJECT)

Bureau of Child Health

ASTHMA INFORMATION CARD

Child's Name _____

Primary Care Physician _____

Child Health Clinic _____

Telephone _____

The treatment plan includes the following medications:

❒ inhaled Albuterol ❒ inhaled Cromolyn

❒ inhaled Beclomethasone

❒ Other _____

ASTHMA INFORMATION CARD

The child named on this card is enrolled in a program sponsored by the City of New York Department of Health, the Columbia University College of Physicians and Surgeons, and the Medical Health Research Association of New York City for preventive care of childhood asthma. The medications prescribed are in accordance with the Guidelines for the Diagnosis and Management of Asthma published by the National Heart, Lung and Blood Institute Publication No. 91-3042, August, 1991.

After treatment, please refer this patient to the primary care physician at the clinic with a note describing the care you administered.

Thank you for your cooperation.

Health Facilitator Telephone Interview (New Mexico Project)

The University of New Mexico • School of Medicine • Department of Pediatrics
Albuquerque, New Mexico 87131 • (505) 277-3072 • 1-800-439-3916

Health Facilitator Telephone Interview

1. What has it been like to have a child with asthma?

   How have you managed as a family?

2. What are the most important qualities or characteristics of a person having this position?

   Have you worked with families previously ? What type of community work or programs have you been involved in?

3. How do you feel about providing encouragement or support for families?

   How would you do this?

4. How would you feel about encountering sensitive issues such as divorce or child abuse in a home?

5. How would you feel about working with an uncooperative family?

6. Discuss personal obstacles:
   Transportation/Safety traveling alone

   Child care

   Will not receive pay in advance/will this be a problem?

   Will this position be manageable for your lifestyle?

7. Discuss monetary reimbursement and inquire what an acceptable amount would be.

8. Education

   Spanish fluency